

PSP/ MATTERS

SUMMER 2022



ALSO INSIDE

**Understanding
eye movements**

**Differentiating
PSP from
Parkinson's
Disease**

**Multidisciplinary
team support**

LIVING A FULL AND

ACTIVE LIFE WITH CBD

WELCOME



I'm finding it hard to believe I started work at PSPA eight months ago, the time has flown by and it feels very much like home. I have been inspired by the team; from volunteers running Support Groups and helping to raise awareness to those of you completing amazing feats to raise vital funds. Added to that the welcome from the staff in the office all helped me to settle in quickly so I could start to plan what the future might look like for PSPA.

I realise I still have so much to learn and over the coming months I'm looking forward to attending some in-person events. Putting people living with PSP or CBD at the heart of what we do is a key theme for me in leading PSPA and now we are allowed to, it will be good to meet people face to face. I have started to book in visits to some Support Groups over the next few months. I look forward to meeting people living with PSP or CBD alongside the volunteers who so generously give their time to making sure the groups happen.

To make sure we continue to put you at the heart of what we do we have two key activities in the pipeline. First we are creating a 'Services Committee' which will consist of patients, carers and Health and Social Care professionals, details are on page 31. Secondly we have just launched a new Patient Survey

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 **<https://farewill.com/pspa-news>**

which will give us vital information from which to develop services and campaign, more details on page 12. Please make sure you complete the survey so your voice is heard and to help PSPA plan the road ahead.

On the services front, the spring has heralded the arrival of four much needed online support groups for Carers. After an initial meeting in March where over 80 people registered it was obvious that there was a need for greater support for carers, if you are interested in joining in you can find more details on page 32.

Also in spring was our annual awareness week from 23 to 29 May with a relaunch of our much loved Ed's Lace campaign. You can read more on page 8.

I look forward to meeting some of you over the coming months.



Rebecca Packwood
PSPA CEO



For more information

all 020 8050 2686

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USEFUL CONTACTS

Main contact **01327 322410**

info@pspassociation.org.uk

Helpline **0300 0110 122**

helpline@pspassociation.org.uk

Fundraising **01327 322414**

fundraising@pspassociation.org.uk

Volunteering **01327 356137**

volunteering@pspassociation.org.uk

Rebecca Packwood, CEO

01327 322413

rebecca.packwood@pspassociation.org.uk



INVOLVING PATIENTS AND CARERS IN RESEARCH

Following the success of our Patient and Carer Voices in Research register, which was established in 2020, PSPA is now keen to take a step forward in what is known as Public Involvement. Public involvement is defined as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them [invo.org.uk].

To move forward in this area, we would like to invite you to join the PSPA Patient Involvement Group. As part of this group, anyone taking part will be involved in shaping study designs, becoming assessors of research funding applications and protocols, and developing informative materials on clinical trials in lay language. Your experience and views of access and coordination of care are essential to improve patient recruitment, retention, compliance, and advocacy in research.

We would welcome patients, carers, family and friends, to join the group. You can register your interest in being involved by emailing research@pspassociation.org.uk

EMERGENCY ALERT CARDS

A new supply of Emergency Alert Cards is now available to order for free.

The cards are an ideal way to hold the name and telephone number of your next of kin along with a few facts about PSP & CBD.

If you would like an Emergency Alert card to keep in your purse or wallet, please contact the Helpline on 0300 0110 122 or email helpline@pspassociation.org.uk. Please specify if you would like a PSP or CBD card.





SOME OF OUR UPCOMING SUPPORT GROUP MEETINGS

If you would like to connect with people living with PSP & CBD and family members in your area, here are a few dates for upcoming Support Group meetings:

Stockport and Cheshire

15 July at 1.45pm at the Bramhall St Michaels Parish Church, Bramhall, Stockport, SK7 2PG

County Durham

18 July at 12.30pm at Woodham Golf and Country Club, Newton Aycliffe, Durham, DL5 4 PN

Hampshire

20 July at 11am via Zoom

North of Wales

9 August at 11am via Zoom

Liverpool

10 August at 1.30pm at The Liner Hotel, Lord Nelson Street, Liverpool, L3 5QB

East Central Scotland

10 August 3pm via Zoom

Isle of Wight

13 August at 11am at John Cheverton Centre, Earl Mountbatten Hospice, Halberry Lane, Isle of Wight, PO30 2ER

Stockport and Cheshire

9 September at 1.45pm at Bramhall St Michaels Parish Church, Bramhall, Stockport, SK7 2PG

Somerset

23 September at 2pm at

Beckington Village Hall, 36 Bath Road, Frome, BA11 6SH

If you would like further information about any of the above Support Group Meetings, please contact our Helpline Team at helpline@pspassociation.org.uk or by calling **0300 0110 122**.

TAKE PART IN A STUDY TO IMPROVE GOOGLE ASSISTANT

A team of researchers is currently looking for people with speech difficulties to take part in their study to improve Google Assistant.

If you are a person living with PSP or CBD and experience speech problems you can help by signing up to take part in the Euphonia project.

The team at the Euphonia Project want to enable people with speech problems to use Google Assistant to control their environment (light on/off, checking who is at the door, adjusting thermostat, etc). As part of the project the team are developing an app that can

transcribe speech with speech problems in real time which they hope will help people be better understood and keep them talking for longer.

If you'd like to take part in the study, please register your interest at <https://docs.google.com/forms/d/e/1FAIpQLSeu8eBOUwzs7PdH25v4ITXjzOVO8rfmfNloUovLForMmYRipA/viewform>

SUPPORT WITH RISING FUEL BILLS

If you are concerned about the rising cost of energy and currently have debts with your provider, please proactively contact them to discuss options.

It may be possible to request a charitable grant and to ensure you are offered the cheapest possible tariffs, ask to be registered on their Priority Service Register.

If you would like to chat about your concerns, please contact our Helpline on **0300 0110 122** or by email helpline@pspassociation.org.uk

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 **TEAMPSA** to **70085** to donate **£5**
- Set up a regular gift online pspassociation.org.uk/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

Recruitment at PSPA has continued in the last quarter, as we welcome four new members of staff to the team.

Here our new team members share a few details about themselves and what they are looking forward to in their new roles at PSPA.



VIVIAN ZHANG – OFFICE ADMINISTRATOR

I am excited to have joined the PSPA team.

After I finished my Master's degree, I worked for another charity and started to discover that I liked to help and interact with people. I then helped

charities as an interpreter at their events and also whilst living abroad, I volunteered at orphanages, helping with their daily life tasks.

I am hoping the knowledge and experience I have gained in the past can benefit the team and provide a meaningful support to the public.



JAMES HOLDEN – COMMUNITY AND CORPORATE FUNDRAISING MANAGER

I'm so excited to be here and help raise funds and awareness for this amazing charity. From bake sales to video game tournaments, yoga to dance nights, talks to walks and to charity of

the year partnerships and everything in between I'm here to help make that happen.

My background is in both Community Fundraising and Supporter Care, and I've worked in the sector for over eight years across a variety of regional and national charities. In my spare time I am a keen cyclist and I'm sure to try my own cycling challenge for PSPA soon!



I can't wait to meet, support and collaborate with all our wonderful supporters. For any fundraising ideas or questions please do drop me an email at fundraising@pspassociation.org.uk and I'm sure we can work together on some fantastic fundraising together soon.



VIVIEN EMEKE-ANANENU – FINANCE ASSISTANT

I am an accountant by training and my work background is in financial services having worked in banking for over 15 years. I joined Team PSPA in December 2021 as a Finance Assistant and I plan to learn more from the role as well as bring my previous skills to the charity.

PSPA is giving me the opportunity to serve humanity especially those fighting PSP & CBD.



MARIANNE FOUNTAIN – HELPLINE CARE NAVIGATOR

Prior to joining PSPA, I have worked as a Social Worker with Adults in Health and Social Care in various settings in the community, and for Parkinson's UK as a Local Adviser for over eight years.

I know how important it is to get the right information and support at the right time. I am looking forward to meeting you all in my role as Helpline Care Navigator and offering support and a listening ear with the rest of the Helpline team.

When not on the Helpline I like to spend time with my family, dog walking, gardening and volunteering.

REGISTERED CHARITY NUMBER 1037087 / SCO41199
PROMOTER: Rebecca Packwood on behalf of PSPA, Margaret Powell
 House, 415a Midsummer Boulevard, Milton Keynes MK9 3BN

GIVE A VOICE RAFFLE

1ST PRIZE: £500 CASH ▪ 2ND PRIZE: £250 CASH ▪ 3RD PRIZE: A LUXURY HAMPER AND HUMMINGBIRD MONTAGE PAINTING. Luxury hamper to be awarded to the individual who sells the most raffle tickets by 31 May 2022

Draw will take place on 15 June 2022. Registered with Milton Keynes Council

Thank You and Good Luck

www.pspassociation.org.uk

TICKETS £1 EACH

NAME _____

ADDRESS _____

TEL NO. _____

Unsold tickets, cash and counterfoils should be returned to PSPA by 31 May 2022.
 Any money received after this date will be treated as a donation and will be used to fund our work.

GIVE A VOICE RAFFLE WINNERS

Thank you to everyone who took part in the Give A Voice raffle. We are pleased to confirm the raffle raised more than £12,500 to help continue our awareness raising, and information and support.

Following the draw, which took place on 15 June, we can confirm the winners as

1st prize – Ticket number 101545 John Copp
 2nd Prize – Ticket number 023650 Peter Cayzer
 3rd Prize – Ticket number 022623 Srini Krisnamoorthy

In addition, a luxury hamper was sent to Priska Wichmann, who sold more than 400 tickets. Thank you.



WEAR ED'S LACE WITH PRIDE IN 2022

The well-loved awareness campaign, Ed's Lace, was relaunched this May as part of our PSP & CBD Awareness Week activities. Here, the original creator of Ed's Lace, Scott Smith, shares where the idea came from and how he and his family feel about seeing the campaign active again.

"You don't easily forget people like my grandad. I often think about him and remember the funny moments we had together. But you, the reader, may also remember my Grandad. Rewind back to 2015 and you may have been one of the 4,000 people that bought and wore an Ed's Lace to raise awareness of PSP & CBD.

I often wonder what my Grandad's reaction would have been knowing there were thousands of bright green shoelaces named after him across the world. If I was a betting man, I reckon he would have laughed, shook his head in disbelief but then told me how proud he was of me.

The sad reality is that I will never know. Eddie died in December 2012 after living with PSP for several years. He died in hospital after developing aspiration pneumonia. It was heart-breaking to see someone I

adored and looked up to leave this world in such a cruel way.

As hard as I try to forget the moment I was told he had passed, I still clearly remember receiving a call from my Mum. Her voice was filled with sadness. 'Grandad passed away this morning, Scott', she said. But as Eddie had taught me as I was growing up, sometimes life is not fair and you cannot dwell on the negatives for too long. You've got to keep your head held high and be strong. He was right. A few months later I moved to Sheffield and started a Masters in Science Communication.

For my dissertation, I approached PSPA to see if I could create videos to help the charity raise awareness of PSP & CBD via their social media pages and amongst healthcare professionals. The charity said yes and I



got to work filming at hospitals, PSPA Support Groups and a charity celebration event in London. I even got to interview MP Kate Green, who was the Shadow Minister for Disabled People.

One night, I had an idea. It came to me as I was sat at a broken table propped up against the wall in my shared University kitchen. I was describing to my girlfriend, now wife, what I had learnt about the scientific process that happens in the neurons (brain cells) of those living with PSP & CBD.

‘It’s like when a shoelace starts to fray’, I said. That was the moment Ed’s Lace was born.

Excited by this seemingly simple simile, I started to share this analogy with family, then friends before finally sharing at a meeting in Towcester at the then PSPA offices. I was overjoyed that everyone seemed to love this idea and within weeks the charity had taken my simple idea of a shoelace and turned it into what we now know as Ed’s Lace.

The idea was that you asked people to buy a green shoelace, swap one of their shoelaces with the green one and cut one end of the shoelace off. Then, over time the shoelace will start to fray. Not in a flash, but gradually. The frayed end of the lace depicts the slow and progressive nature of PSP & CBD.

The charity launched the campaign in Parliament and I still remember being at the network event and hearing everyone talking about my Grandad and wearing bright green shoelaces. People started to question why supporters across the world were wearing a green shoelace in their best work shoes, tangled in their hair, tied around their bags or braided as a necklace. The PSP & CBD community was united in raising awareness of the conditions.

Fast forward to 2022 and all these wonderful memories started to flood back. I received an email from PSPA saying that they would like to relaunch the Ed’s Lace campaign. To say I was delighted was an understatement. I know how much awareness the campaign raised last time. It excited me to think we could do it all over again or even better, raise even more awareness this time around!

I know Ed’s Lace has started countless conversations about PSP & CBD. But we need to continue with the awareness raising. Sadly, there are still thousands of people across the UK that are living with PSP & CBD. Their diagnosis may have been delayed,

and therefore the support is late and at times, substandard. This is not acceptable. People living with PSP & CBD deserve love, understanding and support, not to be ignored.

This support should also extend to the carers and loved ones of those living with PSP & CBD. I have seen first-hand how this disease rips through the family. No one is fully prepared for the fight this disease brings. Thankfully, PSPA can act as a form of armour through their Helpline, Support Groups and information. But carers also need more support to help their loved one live well with PSP or CBD.

Every lace we wear is another conversation or two to help educate and influence more people to support PSPA and get behind people living with PSP & CBD. The more people that understand the devastation PSP can bring and how they can help by supporting PSPA, the better the lives of those living with PSP & CBD will be.

I now have another Eddie in my life. In December 2021, my wife, Hannah, and I welcomed our first child into the world. Eddie Smith is named after my Grandad and I hope he grows up to be the kind, gentle, funny man my Grandad was.

On Christmas Day, my wife and I went to visit my Nan. We gave her a Christmas present from our son and she started to fill up. This was even before she had opened her present. I asked her if everything was OK. My Nan replied: ‘I haven’t had a present from Eddie for nearly 10 years’. We all still miss you, Ed.”

GET INVOLVED

Thank you to everyone who purchased an Ed’s Lace in 2015, 2022 or both! If you haven’t got yours yet, please consider visiting www.pspassociation.org.uk and buying yours today.





PSPA WERE WITH US ALL THE WAY

After years of undiagnosed health issues, Janette Fytche's mum Eileen was diagnosed with PSP in July 2021. Here Janette shares details of Eileen's illness, diagnosis and the support the family received from PSPA.

"Mum was a very strong, active, determined and caring person. She was very much the centre of our family with Ernest, her husband, and our dad. She would always seek times for us all to be together and she showed such immense pride in her family.

She had many friends and was indeed a fun loving, thoughtful and empathetic companion – she stood alongside people at their times of need. Until the start of the pandemic, she regularly organised a village lunch club for seniors, attracting up to 40 diners and providing a service that gave food and company to the older people of the community (even though she herself was over 80!!).

Some time ago, however, mum experienced problems with dizziness and balance. Much later her mobility gradually showed cause for concern along with increasing falls.

The GP was consulted initially but nothing was really suggested about our concerns and her balance problems. She did have various tests but nothing that lead her to a diagnosis which became increasingly worrying and frustrating.

It was clear mum needed to see a neurologist as the falls indicated a mismatch between what the brain was telling the body to do. She was advised that the local hospital had a very long wait for appointments



and so as a family we sought an alternative route via a private appointment. This was secured very quickly with Professor Rowe at The Spire Hospital in Cambridge in February 2021.

By this time mum was relying on a wheelchair to travel any distance and a walking frame around the home (sourced by the family). Her mind was very much active though, just some occasional confusion. At this thorough appointment she was advised to have further tests.

Following these she was referred to Dr Emma Woodberry at Addenbrookes Hospital (fortunately an NHS appointment) and it was this appointment that lead us to the expertise of the Addenbrookes Neurology specialists.

On 19 July 2021 Eileen was diagnosed with PSP by Dr Rittman at Addenbrookes Hospital. We had endured a long wait for the appointment, perhaps due to Covid issues.

Following mum's diagnosis, we as a family set about educating ourselves about PSP. We were given leaflets to read and found PSPA.

We were pleased to find PSPA is a very informative and supportive network of people who cared. I remember them saying 'we are with you all the way' and this was of great comfort at the time. We were sent printed information very quickly and also a guide for GPs which was great and which we passed on.

We knew that the disease was not treatable or curable but we understood that mum could live for maybe six years. But mum's symptoms progressed at an alarming speed. Mum became almost immobile and was unable to access the shower without falling. Dad had the shower adapted but without professional care providers we were unable to use it without a fall and great anxiety for mum. We managed to do daily washing but not without worry. Various health care professionals visited the bungalow, attempted to assess mum's needs and delivered mobility items.

Mum unfortunately became doubly incontinent, something that caused great distress to her. She required frequent changing and washing and the buying of acceptable pads was costly. A continence nurse came to visit and was helpful but the delivery of pads came after mum died. The speech and language therapists (SLT) were also due to visit.

Again, the wait for an appointment meant mum never accessed this service, even though her need was increasing all the time.

Food intake rapidly became a cause for concern – less and less as the days and weeks passed. We tried everything as we just wanted mum to enjoy meals as she had always done. She soon expressed a preference for 'easy' food like cottage pie, yogurt – we now know that she was finding swallowing increasing challenging. It was hard encouraging her to drink enough and we seemed to be constantly heating drinks that hadn't been consumed. A few days before she died she was prescribed special drinks but they arrived too late to be of help.

Mum was admitted to hospital 36 hours before she died. A very caring GP saw the need to do a home visit and could see that mum was quite suddenly totally unable to swallow and was severely dehydrated. She left in an ambulance on the Thursday and died early morning on the Saturday.

From a lack of urgency from GPs (prior to changing practices which was a positive move) to a fight to get any support we can't help but think that the condition and its diagnosis were not acknowledged soon enough. Getting any support in the home seemed impossible. We just wanted to keep mum safe and as comfortable as possible in her own home with those who really loved her. But it seemed to be down to ourselves to source any practical help as Continuing Healthcare Funding seemed difficult to access.

We found mum benefitted from reflexology and would really advocate the use of complementary therapies alongside more traditional treatments. PSP is incurable and having a family member who could administer this was a source of great comfort to mum.

Throughout all of this experience mum remained calm, smiley and accepting of whatever happened.

Sadly, mum's health decline was swift and ever-changing following her diagnosis. She passed away on 11 September.

PSP is a rare and horrible disease. We just want awareness of it to improve, which is why we held a collection for PSPA at mum's funeral. Six members of our family also took part in the Stamford Santa Fun Run in December, raising more than £800 for PSPA too."



INCREASING OUR UNDERSTANDING OF PSP & CBD

This June PSPA launched its latest Patient Survey to help learn more about people's experiences of; diagnosis, care and support, and the quality of PSPA services.

Those of you whose contact preferences are email will have already received a copy of the survey to complete. Those of you who have requested to receive information via post from PSPA will see them dropping through your letterboxes over the coming weeks.

The results will provide an important tool to help PSPA to raise awareness, campaign for improved diagnosis and care and to improve our own services.

The last patient survey was conducted in 2016 so our information is out of date and its vital that we learn about people's current experiences. We want to understand if anything has changed (for better or worse) since 2016 and to use this information to improve the care and support you get in the future.

The survey is designed to be completed by anyone with a diagnosis of PSP or CBD however if this is not

possible it can be completed by the carer as long as the responses are from the person living with the condition. It should take around 30 minutes to complete and can be done in stages.

The information you send back is confidential to PSPA, we do not share it with anyone else. Your responses will be anonymised and grouped with other respondents to produce an overall dataset. We will use this dataset to understand everyone's experiences, and to get your feedback on PSPA.

We would urge as many of you as possible to complete the survey, so we have good quality information to use to campaign for change and to improve the quality and range of services we provide.

We will feed back on the results of the survey later this year.



APPLICATIONS OPEN FOR SMALL RESEARCH GRANTS

Thanks to the generosity of PSPA supporters who donated to our 2021 Research Appeal, applications for our new PSPA Small Research Grants are now open.

As a result of the 2021 Research Appeal, £20,000 is now available to fund research projects looking into PSP & CBD.

Starting in 2022, research proposals of up to £5,000 will be considered. Bigger projects of up to £10,000 may also be considered following discussion with the PSPA Research Committee.

Although an open call for applications, PSPA is welcoming proposals looking into the following priorities, identified in our Research Strategy, which was launched last year:

- **Awareness of PSP & CBD** - How can we better inform GP's, primary care practitioners and the general public about these conditions?
- **Diagnosis of PSP & CBD** - How can we improve development of diagnostic tests, speed up diagnosis rates for people and reduce the incidence of misdiagnosis?
- **Living with PSP & CBD** - How can we ensure the best care is available in the community for both patients and carers?
- **Prevention and causes of PSP & CBD** - How can we help identify the causes by studying the influence of genetic, dietary, or other environmental factors? And through this discover how can it be prevented?
- **Treatments for PSP & CBD** - In the absence of treatments for PSP & CBD what can be done to improve the quality of daily life of people with PSP & CBD, and how can we involve patients in clinical trials?

PSPA Small Research Grants are tenable for between one and 24 months. They will be available to the award-holder only for direct research expenses (including but not limited to research assistant time and equipment, excluding replacement teachings, research lead salaries, computers).



Applications will be considered by a panel of independent research experts who will recommend appropriate projects for funding to the charity's Board of Trustees.

Applications are invited from all career stages and professionals residing in the UK and with a track record of interest in neurodegenerative conditions. Projects led by Allied Health Professionals are welcomed. Collaborative enterprises between two or more teams will be welcomed but are not essential.

HOW TO APPLY

To apply for funding please complete the Small Research Grants application form and return it to: research@pspassociation.org.uk
Or visit our website for more information
pspassociation.org.uk/research/funding-opportunities-for-researchers/pspa-small-research-grants/



UNDERSTANDING AND MANAGING THE EYE MOVEMENT PROBLEMS ASSOCIATED WITH PSP

The loss of control of eye movements associated with PSP, resulting in blurred and double vision, can be quite debilitating.

This occurs because, in PSP, there is an abnormal deposition of clumps of tau proteins in the midbrain, which disrupts the normal functioning of the neural integrator. The neural integrator located in the midbrain is central to the control of eye movements. Like an air traffic control tower, which uses all the information it receives about position of aircraft, weather conditions and available runways to direct aircraft with regards to when and where to land and take off, the neural integrator receives information

from your eyes, ears and balance centres and uses this information to finely control the movement of your eyes. This helps you to (a) focus on stationary objects of interest, (b) follow moving targets and (c) make the world around you look steady while you are moving. All these eye movement functions are disrupted in PSP. However, if we can understand why this occurs, we can optimise the management of these eye movement abnormalities and improve quality of life in PSP.

Saccades are a type of rapid eye movement that brings an object of interest into focus. PSP is characterised by a slower and restricted range of vertical eye movements and saccades, especially downwards. This can result in difficulties in finding objects located in the lower visual field. Potentially, this can be managed using prisms on glasses, which shifts the image from the lower visual field to the central visual field, therefore reducing reliance on the vertical eye movements. However, these prisms are best used when stationary, as they can cause unsteadiness if used while moving.

Similarly, difficulties with double vision when reading are the result of disruption of the control of vergence eye movement, which is the ability to move each eye in different directions. It is necessary to use vergence eye movements to move the eyes closer together to focus on objects for near, or to read. Otherwise, double vision results. Prisms can also be used in this situation to provide symptomatic relief from double vision when reading or performing any tasks that require near vision. In cases where it is not possible to use a prism to correct the double vision, occlusion or blocking out the image from one eye can be used to eliminate the second image. This can take the form of patching one eye or frosting over one of the lenses in a pair of glasses.

There can also be problems with the ability to track a moving target. This is because, patients with PSP cannot accurately generate the fine saccades that are

needed to keep a small moving target in focus. It is easier for a patient with PSP to track larger and slower moving targets. It is preferable, therefore, to avoid the use of bifocal and varifocal lenses in PSP, as these require the use of accurate saccades to be effective. The problems with eye movement control contribute significantly to the problems with balance and unsteadiness that can result in frequent falls in PSP. In addition to the optical options described above for optimising visual function, eye movement and visual awareness training has shown potential to improve balance and steadiness when walking in PSP.

When managing eye movements problems associated with PSP, it is also important to optimise any other conditions associated with PSP that can influence visual function. This includes the provision of lubricant eye drops to treat dry eyes, tinted lenses to manage photophobia and consideration of Botox treatment for blepharospasm (an involuntary blinking and twitching of the eyelids). Each patient needs to be assessed as a whole, with treatment tailored according to their individual circumstances.

Thanks to Helena Lee for writing this article.

FOR FURTHER READING ABOUT EYE MOVEMENT PROBLEMS, PLEASE VISIT:

www.ncbi.nlm.nih.gov/pmc/articles/PMC3008928/
<https://pubmed.ncbi.nlm.nih.gov/19236979/>
<https://pubmed.ncbi.nlm.nih.gov/3729694/>





PSPA SUPPORT GROUPS

Welcome back to face-to face meetings

Our Support Groups provide the opportunity to meet other people living with PSP & CBD, carers, family and friends to share information, encouragement and feel part of a community. A support group member told us:

“It made us realise that we were not alone. Before we found out about the meetings, we knew nothing of the support that was out there. New ideas and practices are discussed, which means we leave the meetings with a new purpose”.

“So, what a delight to see our Support Groups getting back to meeting face-to-face after nearly two years of virtual meetings. The virtual meetings have been successful and have kept us all in touch with each other and have enabled those who are not able to travel to their local group meetings, to at last join in, albeit via a screen. However, there is nothing quite like being able to sit across the table and chat with friends in person.”

Some of our groups have decided to offer a mixture of virtual and face to face meetings so that they can meet as many peoples’ needs as possible. The most valued aspect of attendance at these groups seems to be the ability to share experiences and spend some social time with others. Please do

check our website for information on how your group is meeting.

Our Support Groups provide a fantastic service and are kept going by our dedicated volunteers who not only facilitate the meetings, but also sort out the refreshments and sometimes speakers. We are really grateful to all the volunteers that put in so much time and hard work in organising and running these groups. We could not do it without them. A massive Thank You to you all.

Since the pandemic some of our Support Group coordinators have stepped down from their roles and we are currently looking for people to restart groups in the following areas:

- Sussex
- Essex
- North London
- Nottingham
- West Midlands

If you are interested in setting up a support group, please contact Carol on **01327 356137** or email **volunteering@pspassociation.org.uk**

Let’s see what’s been happening at some of our Support Groups.



POCKLINGTON

Our Pocklington Group, run by Liz Baxter, met in April at the beautiful Burnby Hall Gardens in Pocklington. The sun shone, although a little breezy but everyone enjoyed the fresh air and seeing the amazing gardens and lake. I believe the fish were incredible. Everyone enjoyed the afternoon especially the tea and cake which of course is essential at PSPA meetings.



COUNTY DURHAM

I think the County Durham group should be known as the 'Ladies and Gentlemen Who Lunch'. As soon as Covid restrictions were lifted the Durham group, run by Maria Rodrigues- Hancock, were one of the first groups to get back on track with their face to face meetings. The group meet bimonthly at the Woodham Golf and Country Club where they are treated to a lovely lunch and a chance to meet up and share experiences. Lovely surroundings and good food. Why not join them if you live in the area.



COVENTRY AND WARWICKSHIRE

Jenny Knight has run our Coventry and Warwickshire group for many years. The group met regularly through the pandemic via Zoom to help reduce isolation for those living in the local area. Although they enjoyed their quizzes and catch ups online they are so pleased to be back together again in Kenilworth and Mancetter.

Jenny and her band of helpers, including Sue and Mary, have recently set up a new group in Rugby so if you live in the Rugby area please check our website for meeting dates. They would love to see for a catch up, and of course tea and cake.



SOMERSET

Ancient trees were the centre of attention at the first face-to-face meeting of 2022 for the Somerset group. Denise Hunt, who facilitates the group arranged a speaker for the event and the group welcomed, Julian Hight. Julian is the author of 'Britain's Ancient Forest, Legacy & Lore'.

Above is Denise with Julian and his book as well as some of the attendees at the meeting.



ME AND MY PSP DIAGNOSIS

I am Julia Chappel. I love to laugh. I have four children and eight grandchildren. As I have always been a “doer” and fiercely independent I find my condition with PSP very frustrating. This is the story of my journey towards acceptance and peace as I travel without a map through these uncharted waters.

2018

“In the late summer of 2018, I felt like my flip flops must be getting old and stretched as I somewhat awkwardly walked to the corner shop.

I had been to the GP about why I was feeling dizzy. I was upgrading a house in a nearby village and

just thought I was doing too much! I was given anti psychotics as a remedy for the dizziness. It did help but it meant I couldn’t drive which was really difficult. Little did I know what was to come...

Then, at a routine dental check-up I commented to the dentist that I felt something wrong with the back



of my throat and I was struggling to get the end of a sentence breathing normally. This was beyond the dentist remit and I put it down to the disliking of having to spend four hours on the phone as part of my job, which no one in the team enjoyed.

I had gone to the appointment on my bike and on leaving the surgery I fell off my bicycle into a flower bed (my second fall, I hope nobody saw!)."

2019

"By mid-summer 2019 my health had started to deteriorate. There was nothing I could really put my finger on just lots of little things. One evening, my partner was over and I had remembered him talking about his mother's UTI's and wondered if that was the reason for the urgency I felt to get to the bathroom.

The subsequent GP appointment saw the doctor dismiss my concerns although a blood test was prescribed. When the blood tests came back clear, I knew I needed another appointment to investigate further. The receptionist gave me an appointment for later that same day. Lucky me! Appointments are hard to come by.

The GP did refer me to the neurology department at the local hospital. Unfortunately, the referral was rejected, and an MRI was requested.

The uncertainty of the ongoing nuances, the lack of knowledge and holding it all in were getting to me. I focused on my plans for retirement from my position at the hospital appointments division on 6 September. I would look after my grandchildren while my daughter-in-law trained as a midwife.

On 5 September as a result of the MRI the neurologist, a movement disorder specialist, told me I probably had Parkinson's disease (this will be familiar to almost everyone with PSP) and was given a follow up appointment for an agonising six months' time. I felt at this point it was better to spilt up with my partner, as I couldn't expect him to care for me. That was hard but we are still friends.

By December my symptoms were becoming rapidly worse, and my appointment was brought forward with the neurologist.

At this point I could still walk with an arm swing, although over shorter distances and I had slowed thumb to finger reactions, but it was still doable. The reports of my eyes not opening as normal



seemed to fall on deaf ears. I was put on Parkinson's medication and sent away, bet that's a familiar story to many of you?"

2020

"My daughter, with her usual tenacity and unerring determination to look for answers had found a Danish therapist named Lillian who was convinced that the disease was entirely due to stress. To be honest, I thought so too.

Whilst I was still going to the gym every day, and the therapist and I put in hours of work with each other, I wasn't getting any better. Then, to add to everything, lockdown hit.

There had been a further telephone consultation with the neurologist and a change in medication. The change in medication continued to make no difference whatsoever. By this time I had finally been contacted by the Parkinson's nurse. She had recommended yet another change of medication and also weekly phone calls to support me. None of this support ever happened and I was increasingly feeling let down by the system.

At this point my daughter moved back to England with her family and stayed with me for a few weeks while they found accommodation. This period also marked the end of me driving, I no longer felt safe on the roads.

During this time I had received a letter from the neurologist stating that I probably had "atypical"

Parkinson's. As far as they were all concerned there was nothing else they could do for me and I was left feeling totally abandoned.

My daughter again with her usual tenacity, researched the atypical Parkinsonism and found a doctor in Southampton that specialises in the condition. I think my GP was glad to get me off her back and referred me to the doctor in Southampton. Thank goodness, at last someone was going to help.

It was November by the time I received an appointment to Southampton and I had been ill for over a year. I had tried craniosacral therapy, acupuncture and was continuing to do everything asked of me by Lillian.

At my appointment in Southampton, the neurologist immediately diagnosed PSP (as best they can) with the tell-tale sign of my eyes not being able to follow his finger. I was put in touch with PSPA and the Hampshire group has been a fantastic support network that I am grateful for."

2021

"The support and diagnosis from the hospital at Southampton was a welcome relief. The neuro physio has been a tremendous help constantly answering my emails and going back to the doctor for answers to my questions. The neurologist in Southampton alerted the hospice nearby and they are now on my case.

With the combination of the new GP and the support of Dr Ghosh and his team in Southampton I was suddenly inundated with phone calls, support, help and equipment to make my life easier.

At Easter 2021 I moved to a flat with supported living. I wear a pendant that alerts a member of staff and not the ambulance, as before.

My sister is coming every morning to get me up and often comes back to put me to bed.

My daughter is also involved heavily in my care, coming over often. The feeling of guilt is what is driving me towards relieving the pressure on my family and have a live-in carer.

I have been granted CHC funding (Continuing Healthcare). My live-in care began in the summer after a couple of false starts. This transition and

loss of independence has been one of my biggest challenges. My carer however has wonderful experience, although I am her first patient with a PSP diagnosis so we are learning together.

I now use a wheelchair to get about and my speech has been deteriorating and I have an electronic device to help communicate. I have been researching eye crutches as I continue to find eye closure an issue. Light sensitivity continues, but hey, it means I get to look like a rock star with my glasses on even inside!" It's not all bad though, a catheter means I no longer have to get up at night and the PSP has created inappropriate laughing and crying with everyone laughing along with me.

2022

"I have been burying my head in the sand and not really accepting what is happening to me. When I read this back and what I have written, I sound almost normal and that is how I feel, when my eyes are shut. Nothing could be further from the truth. My journey isn't finished and I continue to be surrounded by the love of my family and the noise of my grandchildren.

If nothing else I hope that this story helps anyone going through the process to know they are not alone. It is certainly a bumpy ride but there are people out there cheering us on and wanting to help. I may not be here as long as I would have hoped but I plan to leave my own legacy and donate my brain to further the PSP cause and find a better solution."

With love Julia x



HOW A MULTIDISCIPLINARY TEAM APPROACH CAN HELP

In this edition of PSPA Matters, we will be sharing the first of many features from healthcare professionals who work as part of a multidisciplinary team (MDT) supporting people living with PSP & CBD.

Here, Dr Boyd Ghosh, PSPA Trustee and consultant neurologist in Southampton and Salisbury, details what an MDT is and how this approach to care benefits people living with the conditions.

WHAT IS AN MDT?

Often people living with PSP & CBD experience challenges with a range of symptoms such as falling, eye issues, swallowing problems, losing weight and speech difficulties. To help the people affected manage their symptoms so they can live the best life they can, they may need support from a variety of different healthcare professionals, not just their consultant.

An MDT therefore is this group of healthcare professionals who are involved in your care. This may include your consultant, a physiotherapist, an occupational therapist, a speech and language therapist, a dietician, a Parkinson's nurse, an ophthalmologist and a palliative care team. There may also be a clinic coordinator.

HOW DOES AN MDT WORK?

There are a variety of models for MDT working, ranging from virtual meetings for healthcare professionals to in-person clinic days where you have the opportunity to see all the professionals involved in your care, in one place, during one appointment day.

At Southampton and Salisbury, our MDT is organised by our clinic coordinator. The coordinator organises regular virtual MDT meetings for all of the healthcare professionals who support people living with PSP & CBD to get together. These meetings are an opportunity to discuss all of our patients and any particular issues that are cropping up at the time. Gaining input from the whole MDT can help to sound out ideas and connect the dots to other symptoms which might be affecting the patient.

WHAT ARE THE BENEFITS OF AN MDT APPROACH?

The main benefit of MDTs is we work together to optimise the patients' function and quality of life, as they adapt to different stages of their condition.

As well as meeting regularly, all the healthcare professionals involved in a patient's care are copied in appointment letters so they can keep up to date with any issues being experienced as well as how they are being supported. This means we can think in a joined-up way, access focused advice from each other as well as learn from each other too.

For people living with PSP & CBD, as well as their carers and family members, an MDT approach can help them to better understand their symptoms as well as which professionals can help them and when.

For those MDTs who are lucky enough to have coordinators, like we do, there is also one main point of contact for both the team and the patient to talk to in between meetings and appointments.

If you are unsure of what to expect from your care, contact the Helpline to receive one of our hand 'What to expect from your care' Guides.





DAY IN THE LIFE OF A PARKINSON'S NURSE SPECIALIST

Coral Mannion is a Parkinson's nurse specialist in Doncaster.
Here Coral shares details about her role and how she supports people
living with PSP & CBD in her area.



"I initially worked in social care housing. During this time, I worked with vulnerable people, such as homeless people, and ex-offenders. I eventually moved into healthcare, working as a nursing assistant on a forensic psychiatric unit. I decided to retrain as a general nurse in 2013 at Sheffield Hallam University. When I qualified I started out as a community staff nurse, which I enjoyed very much.

During my training as a student I had the opportunity to shadow a nurse in the Parkinson's Team and I really enjoyed it, so when the opportunity came up to apply for a role within the team, I jumped at the chance. I joined the Doncaster Parkinson's team in 2018 and a couple of months after becoming a part of the team, we took over the case load of the 'Parkinson's Plus' patients. These patients include patients living with PSP & CBD.

My role as a nurse in the Parkinson's team, is such an interesting role and entails many different activities. This can include: visiting patients in their own home, holding clinics at Tickhill Road Hospital in Doncaster and holding four smaller clinics at GP's surgeries around Doncaster. Covid has changed things somewhat but hopefully we shall be visiting Doncaster Royal Infirmary once again on a weekly basis to coordinate the care with the staff on the wards. Often these medical conditions are not well understood so it's great to get the opportunity to educate and share good practice with other health care professionals. I consider educating myself as very important as well, I'm always looking for different papers to read and courses to attend as things change so quickly and I want to be able to offer up to date evidence-based information so that I can give the best care possible.

Another part of the role is referring patients to other parts of the multidisciplinary team. We are very lucky in Doncaster to have some very experienced physiotherapists and a brilliant occupational therapist as part of the team. They are always on hand when patients' needs have changed.

Education is a large part of the role, be this educating the patients, their families and/or carers, staff at care homes or hospital ward staff. I try to be as accessible and on hand as possible to answer patients queries and if I can't answer a question, I will find someone who can or at least point them in the right direction.

During home visits and clinic appointments, I will assess the patient's medication regime and discuss

their symptoms. We will look at any changes which have taken place and then together work out a plan which suits them. Sometimes this is therapeutic intervention, sometimes it is adapting the medication regime.

As part of my role, I engage with PSPA, I have recently taken on the role of hosting the regional Support Group zoom meeting. This is great as I get to see some of my regular faces, but also, I get to support some of the patients in other areas who don't have access to a nurse. I'm very much looking forward to reopening the face-to-face coffee mornings in Doncaster as I think they offer a brilliant opportunity for patients to engage with people who are in the same boat and benefit from some peer support. It's also very helpful for partners to meet others who are in a similar situation.

I support my newly diagnosed patients by offering a listening ear, adapting their care to suit them and their wishes and needs. I respect those patients who need space and I also make myself available to those who need more support and are struggling to come to terms with their diagnosis. I ensure that the whole family knows that I am there to support them as well as these conditions affect the whole family. I value communication very highly and try to be as open and approachable as possible so that patients and their families feel that they can open up to me and talk to me about anything which is bothering them. I ensure that my patients are aware of PSPA and the support which they can offer. I also keep them informed of the other members of the multidisciplinary team and that they can tap into what they have to offer when the time comes.

My advice to patients who don't have a nurse is to get a nurse as quickly as possible, the nurse will help to coordinate the care between appointments with your neurologist. If your neurologist does not refer you to a nurse, ask if they could or speak to your GP. Ask if they can contact the local Parkinson's team or the local neuro outreach team and they will refer you to a nurse who has experience of movement disorders. If you still struggle to get a nurse reach out to PSPA for further support and they will help."



MAKING A DIFFERENCE WITH CORPORATE PARTNERSHIPS

In January 2021, Talbot Underwriting selected PSPA to be their Charity of the Year for the next two years. Here, Talbot employee, Kelly Hooper, shares her experience of raising awareness and fundraising with her colleagues.



“MUM’S CONDITION DETERIORATED. SHE WAS ONLY 66 YEARS OLD SO IT FELT REALLY UNFAIR. THE SPEED IN WHICH PSP HAD TAKEN HOLD OF MUM WAS SO FRIGHTENING AND IT WAS OBVIOUS HER TIME WAS GOING TO BE LIMITED. ”

“Like most people, I first heard of PSP when my mum was diagnosed. As is all too common, mum was first diagnosed with Parkinson’s. Mum’s PSP diagnosis only came about because her doctor had attended an awareness session on how to identify PSP run by PSPA. The diagnosis was devastating and we felt very alone, scared and confused. But that changed after we got in touch with PSPA. The Helpline was so informative and so helpful, we felt less alone and I now realise just how vital that is.

When we needed to move mum to a nursing home, they contacted PSPA to arrange training sessions for the nurses so they knew what was likely to happen to mum and what they could do to make things easier. It might only be a small charity but it has a huge impact on those needing help and support.

It was around this time that I first fundraised for PSPA. I took part in the Thames Path Challenge. For me it was not just about raising funds but also about raising awareness of PSP. Not a single person I spoke to had ever heard of it and I wanted to change that. I had a target of £300 and was so pleased that I managed to raise over £1,000.

Mum’s condition deteriorated. She was only 66 years old so it felt really unfair. The speed in which PSP had taken hold of mum was so frightening and it was obvious her time was going to be limited. It was at this time PSPA called me, looking for runners to join their London Marathon team. Could I do it? I was a couch potato, and it was the second week of January. The chances of me actually being able to finish were quite frankly unlikely. Strangely I still agreed. I now had 12 weeks to get marathon fit. Completing the race was tiring but I managed to raise over £2,700. The day after completing the marathon the company I worked for agreed to match my fundraising. This meant I raised more than £5,000 for PSPA, I was totally blown away.

My current employers, Talbot Underwriting have a Charity of the Year scheme (although the sponsorship period is actually two years). I nominated PSPA and after hearing from myself, Jon the Trustee, Sarah and

Helen we received 54% of the votes. I cried. I felt so overwhelmed and so unbelievably happy. What a way to mark the 5th anniversary of mum’s death.

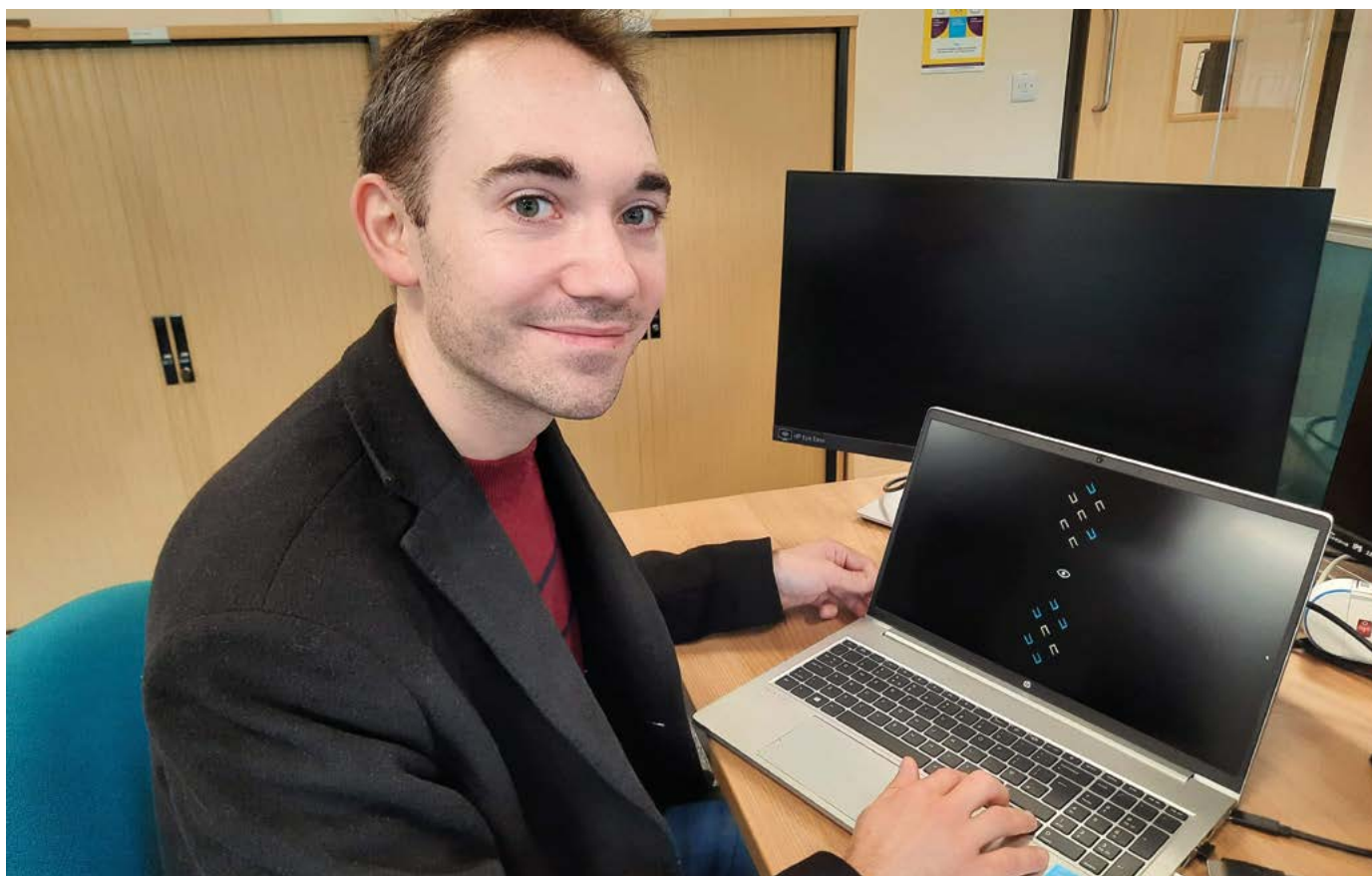
So far we have raised over £80,000 and so many more people now know of PSP. Fundraising has included a valentine’s bake off, an Easter children’s art competition, a Euros competition, a Christmas jumper appeal, and the super-six Talbot dream team of Andy, Craig, Ian, Malvir, Sean and Yung all of who ran the Royal Parks Half Marathon with literally just a few weeks’ notice. The team had an ambitious target and raised over £9,000. During March, Jon Atkinson ran a total of 300km which was just unbelievable, albeit one I am not sure he would repeat. And in April Ollie ran the Brighton Marathon.

Over the months ahead we have a children’s sunflower growing competition, another bake sale, a very ambitious football competition and we are building a team for the October London Marathon. Currently we have Ben, Ed, Greg, Gregg, Harry, Sarah, Shane, Tom and Yung signed up. I noticed with the Royal Parks half, everybody really enjoyed being part of a large team and having support.

Shane however is not just doing the London Marathon, thanks to the help of PSPA, Shane has managed to secure places for Ride London and the Serpentine Swim. This means if he is successful in all events he will also have completed the London Classics, three very difficult events and really no mean feat.

Our corporate relationship has been so very fulfilling and I am chuffed so many people now know of PSP. If you have a Charity of the Year I urge you to put PSPA forward. The team are wonderful to work with and it is so rewarding. I would say, even if your company does not have a Charity of the Year, why not speak to them? The company itself does not have to do anything except support their colleagues doing various challenges and fundraising and PSPA are there every step of the way.”

Email fundraising@pspassociation.org.uk if you would like support fundraising in your workplace.



A NEW STUDY AIMING TO DIFFERENTIATE PSP FROM PARKINSON'S DISEASE USING HOME-BASED COMPUTERISED TESTS

PSP and Parkinson's disease share many symptoms which can make it hard for clinicians to tell them apart.

This can be really problematic for people living with PSP, because medicines that work for Parkinson's disease are not effective at treating PSP and they can experience unpleasant side effects. A misdiagnosis means a person with PSP might take medicine that does not work and experiencing the side effects

unnecessarily. This is also inefficient and wasteful of NHS resources. In 2015, Professor Daniel Smith of Durham University and Dr Neil Archibald of James Cook University Hospital in Middlesbrough undertook a series of exploratory focus groups with people with PSP, carers and clinicians, that identified early



diagnosis as a key concern. This led to a collaborative project aimed at developing new methods of discriminating between PSP and Parkinson's disease.

The research initially focused on the idea that people with PSP might have particular problems with a cognitive ability called visuospatial attention. Visuospatial attention which is the ability to search through a cluttered environment to find a particular object (e.g. finding your keys on a table before you go out). This ability can be tested by asking a participant to search a target among several distractors on a computer screen (e.g., looking for a red circle among blue circles). The initial results were very promising: People with PSP were much slower than people with Parkinson's disease to undertake the tasks. They also found that people with PSP and Parkinson's disease had different problems with short-term memory, which is the ability to hold information in memory over a short period of time (e.g. remembering directions someone is giving you). People with PSP had particular problems remembering sequences of locations when they presented vertically, whereas people with Parkinson's disease were no different from healthy people.

These results are very promising, but the sample of patients was small. One of the reasons for this was that the project relied on people coming to Durham to take part, which can be a problem for people with PSP who often have mobility problems. To try and address these issues Professor Smith and Dr Archibald joined with Drs Alison Lane and Tony Atkinson (Durham University), Dr Clare McDonald (Queen Elizabeth Hospital, Gateshead), Dr Uma Nath (City Hospitals, Sunderland), and Professor Richard Walker (Northumbria Healthcare NHSFT), and secured funding for a new three-year project from the Dunhill Medical Trust. This project will involve a much larger group of participants (aiming for 81 participants in total) by taking the tests to people's homes, rather than asking people to travel to Durham. The project got the green light from the NHS, and in March 2022 the Durham team were joined by a new team member, Dr Alexis Cheviet, who will manage the project.

In addition to tests of attention and memory, the new project will explore other aspects of cognitive function. For example, some recent studies have shown that people with PSP can sometimes have problems recognising emotions, so one of the tests will examine whether emotion recognition is different in PSP and Parkinson's disease. Another test will look at mental imagery (the ability to see pictures 'in the

minds eye'). This is because mental imagery can be affected by eye-movements, which are known to be much more seriously affected in people with PSP compared to Parkinson's disease. The project will also explore whether or not people with PSP are using prism glasses to help compensate for problems with their eyes, and what they think about prisms. This is an important question, because prism glasses could be a relatively cheap and effective tool for helping people with PSP. However, there are almost no scientific studies about prism glasses in PSP, and little evidence about what makes them helpful or not. The team estimate that the tests will take about three hours, split over two appointments. Professor Smith and his team hope that the results of these tests will enable them to accurately distinguish between people who have PSP and Parkinson's disease. If they can, the next step will be to test the diagnostic value of the tests compared with current practice, but this is several year's work away!

The project will be running across the north-east of England from June 2022 until March 2025. If you would like to know more about the project, please feel free to contact Dr Alexis Cheviet (alexis.cheviet@durham.ac.uk) or Professor Dan Smith (Daniel.smith2@durham.ac.uk) at Durham University. Alternatively, visit : motorbiasproject.com/can-cognitive-tests-differentiate-psp-and-parkinsons-disease





HELLO AND THANK YOU

Our amazing volunteers help PSPA provide support across the whole of the UK. Here we say a big 'Hello and welcome' to two new volunteer Support Group Coordinators who are providing support to families in their local area.



JON GARRARD

Jon is already a familiar face to some of you as he has chaired two of our Family and Friends Days as well as being a PSPA Trustee. Jon originally joined PSPA in 2014 when his dad, Chris was diagnosed. Following that diagnosis Jon and his family

were regular visitors to the Kent Support Group and found the group a great source of information and

support. Sadly, Chris passed away in 2018 and since then Jon has supported PSPA with numerous projects and has been a relentless fundraiser.

Jon has now decided to try his hand as a Support Group Coordinator for our Kent Support Group. Jon explains why he wants take on the role.

"As a family we got so much care from the Kent Support Group, it really helped us to feel less alone, so for me it was a must that this support continues,



dad lived his life for the benefit of others and I'm proud to follow the example he set for me." Welcome Jon.

Kent Support Group meets at Badgers Mount Memorial Hall, Highland Road, Badgers Mount, Kent, TN14 7AU

Dates of the meetings can be found on the PSPA website



LOUISA AND SALLY

Thank you to Louisa Roberts West and Sally Reynolds, who together have been running the Hampshire Support Group since the summer of 2013. Here they both share why they started volunteering for PSPA and what they enjoy most about coordinating the monthly group meetings.

Louisa: "After my mum died of PSP, I knew I wanted to volunteer for PSPA. Once I'd found the perfect venue in Hampshire, I got the Support Group up and running by May 2013. The group quickly grew and we now attract around 20 people who regularly attend. These are a mixture of current carers, people living with PSP & CBD and ex-carers. People come for the friendships which are built in the group and they often socialise and stay in touch in between meetings, which is great to hear."

Sally: "I got involved with the Hampshire group from the second meeting. I attended with my husband Ted in June 2013, after he was diagnosed with PSP. We generally have a discussion topic for each meeting, and we cover all sorts of subjects. We also have a range of local organisations who drop in to give talks, and companies who demonstrate equipment. We've also held book swaps, wellness sessions and we organise excursions to local accessible gardens and garden centres. Since the pandemic, we offer both

face to face and Zoom meetings so we can reach out to as many people as possible."

Louisa adds: "Organising the Hampshire Support Group meetings is incredibly rewarding. Being able to see the difference the shared knowledge, experiences and support makes, is amazing."

The Hampshire Support Group is next meeting on
20 July, 11am via Zoom
7 September, 11am at Wherwell Village Hall

HOW YOU CAN HELP

Volunteering for PSPA can be extremely rewarding. It offers the chance to make a difference to those affected by PSP & CBD as well as providing an opportunity to develop new skills or build on existing experience and knowledge.

If you would like to volunteer with PSPA, there are a range of roles available which may interest you:

EDUCATION VOLUNTEER

Use your personal experience of PSP & CBD to help educate and train health and social care professionals so they better understand the conditions, the changing needs of those affected and how they can provide the best care possible. To do this our Education Volunteers give talks about PSP & CBD to health and social care professionals in their local area, in person or via Zoom.

EVENING HELPLINE VOLUNTEER

Help to support families coming to terms with a diagnosis or planning for the future. Evenings in particular are a popular time for family members caring for a loved one to call for support, sometimes with a particular question in mind or just to chat to someone who understand what they are experiencing.

LINK VOLUNTEER

Help reduce isolation by supporting people living with PSP & CBD in your area in person, by telephone or email.

MICRO VOLUNTEERS

Provide a friendly welcome at our Family and Friends Days or cheerful energy at a challenge event cheer point as a PSPA Micro Volunteer. You might support specific events lasting half a day to a whole day, so if you don't have a lot of spare time but you still want to help, this role is perfect for you.



PSPA SERVICES COMMITTEE MEMBERS (VOLUNTARY ROLE)

PSPA are looking for members to join their new Services Committee

We continue to shape our services to meet the needs of those we support to ensure people with PSP & CBD continue to live well, can access the right services at the right time and do not feel alone.

We want everyone we support to have an opportunity to be involved with our work in more meaningful ways.

We are now seeking members, including healthcare professionals, people living with PSP & CBD, carers and family members, to be part of this exciting new committee. The committee will support us to ensure services are needs led, effective and can help us prioritise our limited resources. Details of the meetings will be fed back to the PSPA Board of Trustees.

The committee will meet twice a year and attendance will be either face to face or virtual, whatever is easier for members. In addition to attending meetings, members will need to read agenda papers in advance of the meetings to contribute to discussions.

We welcome applicants from diverse backgrounds

and would particularly value people with any of the following- although this list is not exclusive:

- Experience of PSP & CBD
- Experience of social welfare and/or health services
- Knowledge of safeguarding issues
- Project management and/or strategy development skills
- Experience and an interest in voluntary sector services for disadvantaged people.

HOW TO APPLY

To register your interest: please send an email or letter explaining:

1. Why you would like to become a PSPA Services Committee member?
2. What you think you could offer people living with PSP & CBD?

If you wish to have an exploratory conversation with us prior to formal application, please contact **carol.amirghiasvand@pspassociation.org.uk**. The closing date for applications is 26 August

SUPPORTING PEOPLE LIVING IN SCOTLAND

To ensure we support people living across the UK, we have made some changes to our Helpline support in the devolved countries. Jules Brown, Helpline Manager is now covering Scotland, Wales and Northern Ireland.

Here, Jules updates us about the support available in Scotland.

NEWS FROM GLASGOW

In April, I attended a new Atypical Parkinson's clinic which started earlier this year at Queen Elizabeth Hospital in Glasgow. The clinic is led by neurologists Victoria Marshall and David Anderson. As this is a Multi-Disciplinary clinic (MDT) patients are able to be seen by a physiotherapist and a movement disorders clinical nurse specialist during their visit. There is also an opportunity to chat with me, to learn more about the support PSPA provides and for carers to speak to a representative from Carers support to ensure that they are aware of and are able to access services locally.

As well as visiting the clinic four times a year, when clinic days focus on PSP & CBD, I also attend monthly virtual MDT meetings with the Glasgow team.

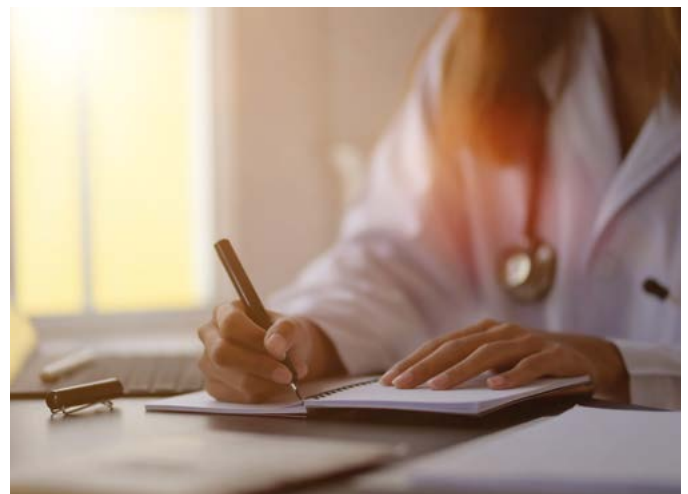
I am hopeful there will be an opportunity to attend other similar clinics in Scotland in the future and to continue to grow close links with neurologists and other health and social care professionals across the country.

NEWS FROM THE NEUROLOGICAL ALLIANCE OF SCOTLAND

I joined a policy group zoom meeting earlier this year hosted by the Alliance, where the group were joined by Andrew Montgomery, National Engagement Lead, Social Security Scotland.

Andrew was able to answer questions and clarify points raised about the national rollout of changes to disability benefits in Scotland from August this year.

Personal Independence Payment (PIP) and Disability



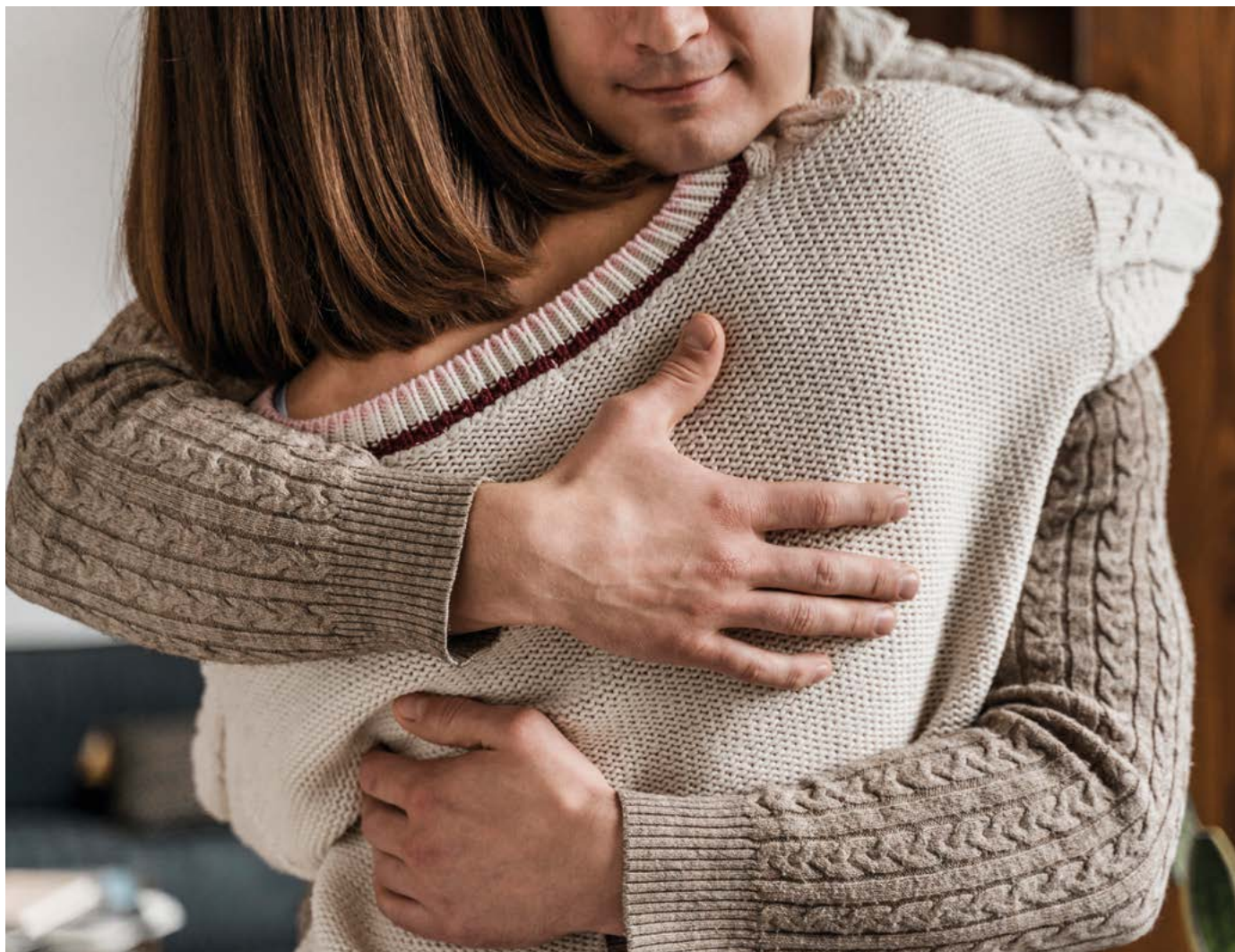
Living Allowance (DLA) for adults in Scotland are being replaced with Adult Disability Payment.

People won't need to apply for Adult Disability Payment if they are already receiving either PIP or DLA for adults, Social Security Scotland will move people across without them having to do anything. The moving across from PIP or DLA for adults to Adult Disability Payment will begin in August 2022 and all those already in receipt will be sent a letter explaining what will happen when the transfer takes place.

The Department of Work and Pension (DWP) will continue to pay PIP and DLA for adults until Social Security Scotland start to pay recipients.

For more information visit www.mygov.scot

If you live in Scotland and would like to talk to Jules, she can be contacted on **0300 0110 122** or email helpline@pspassociation.org.uk and mark the email for her attention.



CARERS MATTER

PSPA Carers Support Groups Launch

Spring 2022 has seen PSPA launch a series of online 'Carers Support Groups'. This follows the success of a trial session at the beginning of March, when 80 carers from across the UK joined together on Zoom.

Clearly showing carers would like the opportunity to meet, we are following up over April, May and June with smaller groups for each region per month, trying out a mixture of evening and daytime options.

Recognising how isolating it can be to care for someone living with PSP & CBD, there is a great benefit to strength in numbers. Whether you want

to share your situation, ask questions, provide ideas, learn new tips or be in the background to simply listen in, everyone is very welcome to come for the whole meeting or drop in and out as they need to.

Each session has a loose subject, April's began with 'Energy Conservation' looking at practical techniques and sources of support to help reduce the physical fatigue and emotional stress that carers often encounter. May's themed covered 'Dealing with Anxiety and Using Relaxation' and June's was 'Sleep'. It doesn't matter how often we go off topic, the groups are your own, and are about what you need to focus on at the time.

AIMS

The aims of the Carers Support Groups are to:

- Learn from each carer's expertise of looking after loved ones with PSP or CBD
- Reduce the isolation and loneliness carers of those with PSP & CBD can experience
- Introduce carers of loved ones with PSP & CBD to each other and develop support networks
- Provide excellent quality information on help available and signpost carers
- Be a safe outlet for carers to be seen, say how they feel, be heard and valued
- Encourage and support each other.
- PSPA also provide a range of other support for carers.

If you would like to join us at one of the carers support meetings please contact **volunteering@pspassociation.org.uk**

CARER'S ASSESSMENT

You may not readily think of yourself as a carer because looking after your loved one is about so much more than doing a job. However, you are formally acknowledged and entitled to a carers assessment, no matter how long you have been caring or what you do. Every county or borough area across the UK has a local carers association or adult social care professionals who are able to provide this for you. Carer's assessments are not to check how good you are but to find out what you need, what benefits such as council tax reduction and respite you are entitled to, and inform what local help and activities are available.

MORE SUPPORT

From our Helpline, online pamper sessions, podcast and carer's stories. Visit **www.pspassociation.org.uk/information-and-support/for-carers** for more information. If you have any questions, please do get in touch.

CELEBRATING CARERS WEEK

Every year PSPA celebrates Carers Week to ensure family and friends who are looking after a loved one with PSP or CBD feel seen, heard and valued.

In 2022 we celebrated Carers Weeks in a variety of ways online.

During Carers Week 2021, we were lucky enough to launch the new PSPA Podcast for carers. This year, as well as marking the 1st anniversary of the podcast, we also offered a Carers Week episode with our Carers Support Group facilitator Jacqui Ede to celebrate carers and talk listeners through support such as carers assessments.

In addition, the episode covers conserving energy and recommendations for ensuring carers get time for themselves. At the end of the podcast, Jacqui also kindly offers a ten-minute relaxation session for listeners to enjoy. If you'd like to skip through to the relaxation session, you'll find it at 32:28 minutes.

The Carers Support Groups are now taking place regionally, and during Carers Week we highlighted up coming meetings to help reach and connect as many carers as possible. In addition, we also sign posted to ways to help reduce carers stress and encouraged people to sign up to Carers UK's 'The Importance of Journaling' webinar on 27 June.

Then to help close the week, PSPA Volunteer Caroline Woodcock, kindly hosted a free Carers Pamper session via Zoom on Sunday 12 June, with a second session planned for 23 June.

If you would like to join us at one of our carer support meetings, please contact **volunteering@pspassociation.org.uk** under aims and above Carer's Assessments.



A HAPPY MEMORY OF WHEN CLAIRE AND HER SISTER VISITED THEIR DAD AT THE RAF BENEVOLENT FUNDED PRINCESS MARINA HOUSE, IN RUSTINGTON.



RUNNING THE LONDON MARATHON IN MEMORY OF DAD

Claire Witts is one of our team of 44 runners taking part in the London Marathon this October. Here Claire shares with us why she wanted to run the marathon and how her training is progressing.



“SO, THE LONDON MARATHON HAS ALWAYS BEEN AN AMBITION OF MINE BUT I’VE JUST NEVER COMMITTED TO IT. THIS YEAR, HOWEVER, IT FEELS LIKE THE CIRCUMSTANCES ARE FITTING TO RUN IN MEMORY OF MY DAD WHO LIVED WITH CBD.”

“I caught the running bug around 20 years ago, after watching my brother-in-law complete the London Marathon. I was so inspired, I started running the next day and haven’t stopped.

So, the London Marathon has always been an ambition of mine but I’ve just never committed to it. This year, however, it feels like the circumstances are fitting to run in memory of my dad who lived with CBD.

Dad was a husband, a father of three, a grandfather and a stepfather. He was artistic and enjoyed cooking, music and travel. Me and my sister have happy memories of driving to the South of France for our summer holidays with the Eagles as the soundtrack of our youth!

He had a hugely successful career in the RAF as a pilot that took him all over the world and was awarded the ‘Distinguished Service Order’ for his bravery in the Gulf War. After he retired from the RAF he went on to have another successful career as Financial Director at University College School in London. He was forced to retire early as a result of his CBD.

Dad experienced symptoms for about five years before he was finally diagnosed with CBD in 2015. It began with him catching/tripping on his left foot as he walked and he began to drop things from his left hand. His behaviour changed and he became quite emotional. Where he had always really enjoyed driving he became stressed and drove erratically. He was a large man and suddenly lost a lot of weight which was quite shocking. At this point, he was referred to a neurologist.

The diagnosis confirmed our worst fears, that there was nothing anyone could do to stop this and that it would only progress horribly. He lived some distance away so visits were difficult. His symptoms progressed and each time I saw him his deterioration was evident. His communication was harder to understand until he was unable to communicate at all and I was unsure what he was aware of.

Sadly, dad passed away during the summer of 2020. Like many families, whilst dad was ill we all felt a sense of helplessness. So, running the marathon in his memory, helps me to feel I am contributing to awareness of CBD as well as ensuring support continues for families too.

Before I signed up for the London Marathon, I would run about three times a week. I have completed a few half marathons previously, but a marathon is another level!

To prepare for this massive challenge, I’ve looked at loads of marathon training plans and then written my own which feels more realistic and achievable for me. I’m currently on target and feeling optimistic! I’m lucky to have a lovely sister who also runs so she supports me in my training for the most of it.

I’ve also got some really generous sponsors, who have helped me to raise £1,770 so need to fulfil my end of the bargain now. No pressure!

On the day I am mainly looking forward to crossing the finish line! No, seriously, just soaking up that amazing atmosphere and just trying to enjoy each mile.”

CHRIS MITCHELL ENJOYING THE SUNSHINE ON HOLIDAY



“CBD HASN’T STOPPED US LIVING A FULL AND ACTIVE LIFE.”

Keith Mitchell was determined to help his wife Chris maintain an active life following her CBD diagnosis. Here Keith shares how they keep adapting their activities according to the changing challenges CBD brings.

“Chris was diagnosed with CBD in 2017 after she began experiencing a few small changes in her behaviour. Mainly, she seemed to find holding onto small things difficult. We played cards and she started to drop them, and she struggled with zips and small buttons on her clothing. As time went by, Chris also started to write addresses upside down on envelopes, had memory issues and had started to show signs of an alien limb.

As a couple, we had always been quite busy with hobbies and socialised with friends and family regularly. Despite the increasing challenges CBD has brought, I was determined we would try and maintain the same, full and active life, even though that has meant adapting the activities, as symptoms progressed.

Initially, Chris was still fairly mobile, so we kept up with playing cards (with my help), our walking group and playing bowls several days a week. But as Chris’s mobility declined we’ve had to look at different ways to remain sociable and active.

Following the diagnosis, we were sign posted to PSPA. Their Helpline has been very useful for sounding out lots of day to day questions, and we began attending our PSPA Support Group, every six weeks. There were two other couples there living with CBD, so it has been useful to chat, share information and tips together.

We recently moved into a retirement flat, as getting over the threshold of the house was becoming difficult. This has been a good move as the flat has



level entry and we're straight out to the garden or car park. We've got to know a lot of people and we're closer to the bowls club too.

Now Chris uses a wheelchair to get about, we don't join the walking group anymore. I still bowl and Chris often comes to watch and chats with friends. We've also started to attend a weekly dance and fitness class ran by Parkinson's UK locally. Chris can't do a lot but we both give it a go. It is good fun and Chris loves the opportunity to interact with others who attend.

As big theatre lovers, I was pleasantly surprised to find on booking accessible seats for Chris, that as a carer I get a free ticket. We went last week and enjoyed a great country and western show.

Being prescribed Donepezil, has helped to improve Chris's memory. She still struggles with remembering what happened yesterday but we can have a good chat about our past theatre trips and plans for the days ahead.

We are really fond of UK holidays and we try and get away three times a year. We often stay in accessible caravans or lodges. They tend to have everything we need so I only really need to take along extra bits like waterproof sheet protectors, the pull up pants we prefer (self-funded but we find they are easier than the NHS provision) and a portable commode, in case anywhere we visit has inaccessible loos (also great for using when visiting friends and family).



Last year we got away to Porthmadog in North Wales, Llandudno and also the Lake District. Chris was born in Ulverston so it was nice for her to go back. Whilst at the lakes, we visited local places, drove around to enjoy the views and spent time in the grounds and nearby pub at the Beatrix Potter house (the house, unfortunately isn't very accessible).

This year, we have two trips booked. In May, we enjoyed an excellent holiday in Ravenstonedale, Yorkshire Dales, where we stayed in an accessible bungalow which is attached to a B&B. In October we will be off to Windemere to stay in a hotel to celebrate our 57th Wedding Anniversary. I have found a company called Warrington Disability Partnership very useful for finding accessible accommodation for our trips.

To aid our trips and social life, I recently changed my car. Chris and I were finding it increasing difficult to transfer her from her wheelchair into the passenger seat. By chance one day I saw someone with a Wheelchair Adapted Vehicle (WAV) where the wheelchair user was pushed up a ramp and secured in the back, and thought it was a wonderful idea so got one. This made things so much easier for us however, I updated the vehicle to one where Chris can sit alongside me. Particularly for longer drives, it is nicer to be able to sit side by side and chat during the journey.

To keep Chris as involved as possible, I ensure she helps with the planning of our trips and car changes. I encourage her to be active in the decision making although she has become a lot more relaxed with the CBD so she often says it is up to me. We often chat at the end of the day to go through the next day's plans and upcoming trips. A nice way to wind down as we get ready to sleep."

PSPA'S COMMUNITY CHAMPIONS

Every year, individuals and families get out in their communities to raise much-needed funds for PSPA. Here is just a small selection of some of the community champions who have raised funds for PSPA in 2022 so far.



This January, ten amazing PSPA supporters donned their woollies to take a Winter Walk for PSPA in London.

The route saw the walkers take in some of London's most iconic sights whilst also raising awareness of PSPA by wearing their purple t-shirts throughout.

Together, the ten walkers **raised more than £10,000 which is amazing. Thank you!**

Cathy Hunt and family who last weekend completed the Manchester 10km.

Cathy ran with Megan, Natalie, Gareth, Francis, Rose and Paul in memory of their Uncle who sadly passed away from PSP. Cathy's uncle would have turned 70 this year which is why they chose a team of seven to run 10km.

Together the team **raised more than £1,700, which is great. Thank you!**



CATHY HUNT AND FAMILY



Jade and Kayleigh completed the Yorkshire Three Peaks Challenge in May.

The sisters completed the challenge in memory of their grandad who passed away from PSP a few years ago. Together they have **raised more than £820! Thank you!**



Janine Jones who ran her first ever half marathon at the end of March.

Janine ran for her dad who has been diagnosed with PSP and he was there at the finish line to meet Janine as she finished.

As well as a massive running achievement, Janine has also **raised more than £1,500 for PSPA too. Thank you!**



ELLA TAYLOR AND HER FRIENDS AND FAMILY



Ella Taylor and her friends and family for taking part in the Wirral Coastal Walk on Sunday 23 May.

The group took on the 12 mile walk to raise funds and awareness after Ella's mum was recently diagnosed with CBD.

Together they have **raised more than £1,700, which is fantastic. Thank you!**

JANINE JONES



Neil Hampshire's family kindly held a collection at his funeral in February to celebrate his life and support PSPA's research into the disease. Neil's wife Debbie, said: "Neil was 68 years old and lived with a diagnosis of PSP for about eight years. Until two years ago he was quite active, but recently he deteriorated quite quickly. Neil kept positive and was a very happy person. I asked for donations at his celebration of life so it could be used for research to help with the disease in future."

Thank you to Neil's family and friends for their kind donations to PSPA.

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

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