

AWARENESS EDITION

# PSPA MATTERS

MEMOIR INSPIRES  
PEOPLE TO RAISE  
AWARENESS OF  
PSP & CBD

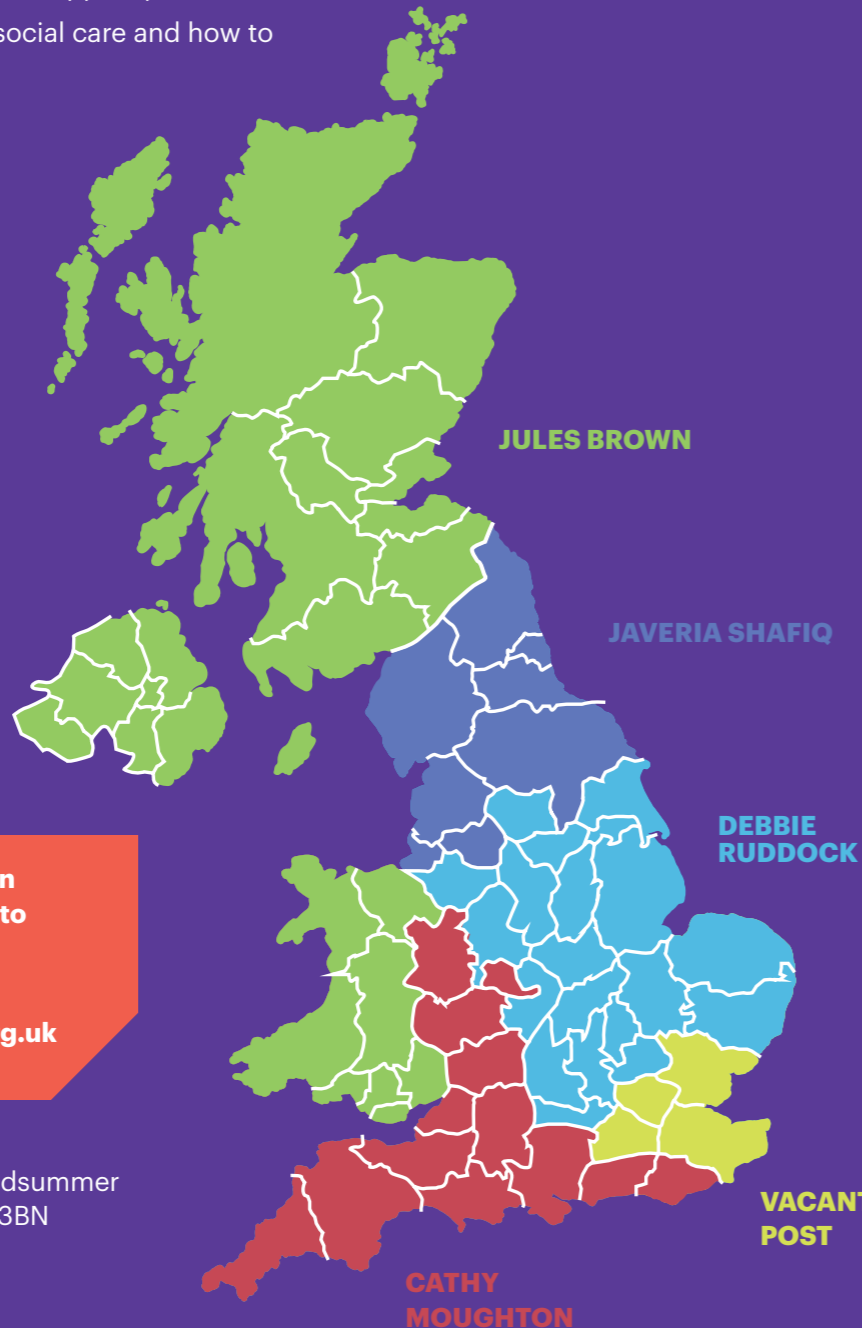
TURN TO PAGE 12



# HERE FOR YOU

**Our Helpline Care Navigators are here to support everyone affected by PSP & CBD. Each Helpline Care Navigator has a designated area (see map) where they 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 to 9pm.**

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

**PSPA**  
Margaret Powell House, 415a Midsummer Boulevard, Milton Keynes, MK9 3BN

Registered charity number England and Wales 1037087 and Scotland SCO41199.

# WELCOME

Welcome to our second themed edition of PSPA Matters for our 30th Anniversary year. This edition focuses on awareness raising, which we know is essential to improving diagnosis through to improving standards of care.

This year we've made additional investments in awareness raising as part of the strategy we launched last year. We have appointed a Director of Policy and Influencing, Mark Jackson, whose role is to build and develop relationships with key policy makers and industry leaders. You can hear directly from Mark on page 21. I know he would welcome people from our PSP & CBD community getting in contact to share their experiences or problems they've encountered. It is vital that we work in partnership with people affected by PSP & CBD to ensure we are focused on what matters most to them.

Our first task is to produce an awareness raising strategy to identify where we can have the biggest impact. Alongside this we will build stronger relationships within the healthcare system and with professional bodies that reflect the priorities in the strategy.

To get our awareness raising work moving we started the year with the launch of the film made in collaboration with the ITN business hub and The Brain Charity - 'Inside Neurology: Our Unique Brain'. The film has been viewed more than 340,000 times and we continue to use the resource to raise awareness. Thanks to Bruce, Neda and their family for taking the time to tell their story of living with CBD. The film was followed by some local press coverage featuring our supporters sharing their experience of CBD. We also had an advert in Acuity magazine from the College of Royal Optometrists, featuring our Eye Red Flags poster to raise awareness of eye signs of PSP in the optical community. You can read more about the film on page 32.

Finally, our PSP & CBD Awareness Week is coming up 17 to 23 June and I hope you can join us by taking part in some of the activities outlined on page 8. By uniting together behind these activities we can show our strength against PSP & CBD.

*Rebecca*

**Rebecca Packwood**  
PSPA CEO



# CONTENTS

- 04 PSPA NEWS
- 06 #WECARE AWARENESS CAMPAIGN
- 10 CHRISTINE NUNN, A CARER'S STORY
- 12 THE SALT PATH
- 18 CONTINUING TO SHINE A LIGHT ON PSP & CBD
- 19 I STRUCK GOLD THAT DAY
- 20 AWARENESS - OUR STRENGTH IN NUMBERS
- 21 INTRODUCING OUR DIRECTOR OF POLICY AND INFLUENCING
- 22 WHY I'M PASSIONATE ABOUT RAISING AWARENESS
- 24 OUR STRATEGY ONE YEAR ON
- 26 CELEBRATING 30 YEARS OF PSPA
- 28 GILDA THORNTON - LIVING WITH CBD
- 32 INSIDE NEUROLOGY: OUR UNIQUE BRAIN
- 34 AWARENESS DRIVES RESEARCH
- 36 THE SYSTEM CAN'T KEEP UP WITH THE CONDITION
- 38 THANK YOU TO ALL OUR SUPPORTERS
- 40 PSPA 30TH ANNIVERSARY SHOP

## USEFUL CONTACTS

- Main contact **01327 322410**  
[info@pspassociation.org.uk](mailto:info@pspassociation.org.uk)
- Helpline **0300 0110 122**  
[helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)
- Fundraising **01327 322414**  
[fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk)
- Volunteering **01327 368597**  
[volunteering@pspassociation.org.uk](mailto:volunteering@pspassociation.org.uk)
- Rebecca Packwood, CEO  
**01327 322413**  
[rebecca.packwood@pspassociation.org.uk](mailto:rebecca.packwood@pspassociation.org.uk)
- Helen Chapman, PSPA Matters Editor  
[helen.chapman@pspassociation.org.uk](mailto:helen.chapman@pspassociation.org.uk)
- Megan Hodgson, Research Coordinator  
**01327 322418**  
[research@pspassociation.org.uk](mailto:research@pspassociation.org.uk)



# PSPA NEWS

## MEET LAVONNE

Meet Lavonne McCormack, our new Volunteer Coordinator. Lavonne recently joined the team to oversee the wide range of volunteers at PSPA. She is currently recruiting link volunteers to support people living with PSP & CBD and their carers.

Lavonne said: "It's great to be back in the charity sector and working for an important cause where I can make a difference. My current focus is on developing our Link Volunteer Service. Our link volunteers provide one-to-one support to people living with PSP or CBD, or their carers during times of crisis.

"People in need of additional support will be referred to us. We then aim to match them with a link volunteer in their area, who will visit or call and provide emotional support, information on the condition or signpost to other organisations for help.

"My aim is to build up the number of volunteers so that we can offer this service across the UK."

**If anyone would like to talk to Lavonne, please contact [volunteering@pspassociation.org](mailto:volunteering@pspassociation.org) or call 01327 368597.**



## MEET NAOMI

We are delighted to introduce you to Naomi Boles, our new Fundraising Coordinator. Before joining the fundraising team at PSPA, Naomi ran a social enterprise bakery helping people facing socio-economic barriers to employment access training and employment opportunities.

Naomi said: "I've always wanted to work in the charity sector, and this role will allow me to learn more while raising funds and awareness of PSP & CBD. My role at PSPA is a new role, and as Fundraising Coordinator I'll support both the Corporate and Community Fundraising Manager and Challenge Events Manager in the run up to big events like the London Marathon, but also on community events like bake sales. I'm keen to build relationships with our wonderful supporters. My first project is the Walk for Hope 2024, which is particularly exciting because any money raised will be matched by a generous donor.

## REGISTER YOUR WALK FOR HOPE TO RAISE AWARENESS

This PSP & CBD Awareness Week get together with family and friends to host a Walk for Hope.

We would love to see supporters all over the UK getting involved in creating or joining a walk and our 30th Anniversary year is the perfect opportunity to do so. However you want to complete your event, be it a walk, jog, bike, stroll or going out in your mobility scooter, challenge yourself to raise awareness and funds for PSPA.

Walk for Hope is a 5km walk, but if you would like to make the distance easier or more challenging, it is completely up to you. To help make an impact on your walk, each sign-up receives a free PSPA t-shirt.

We also have another big reason for you to take up the challenge in 2024. A generous donor has offered to match fund whatever our supporters raise completing a Walk for Hope up to a total of £30,000! So, we need as many people walking as possible to help double the money raised.



**TO SIGN UP VISIT:**  
[WWW.PSPASSOCIATION.ORG.UK/EVENTS-LIST/WALK-FOR-HOPE/](http://WWW.PSPASSOCIATION.ORG.UK/EVENTS-LIST/WALK-FOR-HOPE/)

## A GIFT THAT GIVES TWICE

We've recently expanded our range of items to include a wellbeing range. Not only do these items make you feel good, they also help PSPA too!



LEMON TREE DIFFUSER



EMERALD BEES SCENTED BOX CANDLE POT



BLUE WOVEN STAB STITCH COTTON THROW

**To buy visit**  
[www.pspassociation.org.uk/fundraising/shop](http://www.pspassociation.org.uk/fundraising/shop)

SCAN THE QR CODE TO NOMINATE



To make a nomination please scan the QR code or visit [www.pspassociation.org.uk/information-and-support/pspas-30th-anniversary/30th-anniversary-awards/](http://www.pspassociation.org.uk/information-and-support/pspas-30th-anniversary/30th-anniversary-awards/)

## 30TH ANNIVERSARY AWARDS

In our 30th Anniversary year we have launched the 30th Anniversary Awards to thank and celebrate members of our PSP & CBD community. As we reported in the last edition of PSPA Matters, these special awards are to recognise all people within our community, including people diagnosed with the conditions, carers, volunteers, fundraisers and family members.

### The award categories are:

- Always Amazing Award for someone living with PSP
- Always Amazing Award for someone living with CBD
- Caring Award for an unpaid carer, family member or friend
- Volunteering Award
- Fundraising Award
- In-Memory Award

**Nominations close on 23 June.**



# HELP SHOW #WECARE THIS AWARENESS WEEK

This year, for our annual PSP & CBD Awareness Week, 17 to 23 June 2024, we are shining a light on carers of people living with PSP & CBD



In 2024, we want to raise awareness of the incredible support carers give to people living with PSP & CBD, as well as the challenges they face – and to make the case for better support for carers. During Awareness Week please get involved and help us improve support for PSP & CBD carers.

Unpaid carers are a lifeline for many people living with PSP & CBD. Whether a partner, parent, child, family member or a friend, people living with the conditions often rely on a loved one for their care. From help with day-to-day activities to supporting healthcare

professionals and providing emotional support, the average carer in the UK provides more than 26 hours of care and support every week – with many providing even more.

The value of unpaid carers is enormous, and not just to the loved one they're caring for. Carers bridge gaps in state-funded support and reduce pressure on services like the NHS. It's estimated that unpaid carers provide more than £162 billion worth of care a year in England and Wales alone – that's £445 million a day.

**UNPAID CARERS PROVIDE MORE THAN  
£162 BILLION WORTH OF CARE A YEAR  
IN ENGLAND AND WALES ALONE**

Despite this value, however, carers of people living with PSP & CBD often face significant challenges. Many struggle to balance providing care with their own lives or with working, have difficulties getting breaks and respite from caring, and face barriers when helping their loved one deal with services like the NHS or other state support. Nearly three-quarters of carers in the UK say they're worried about their finances, and 61% say they need more support to look after their own health and wellbeing.

## Why we're showing #WeCare

At PSPA we recognise the vital role that family, friends and other carers play in supporting people living with PSP & CBD. We know that many people living with the conditions simply couldn't cope without the support of their carers. We also recognise that carers need a better deal.

Our Helpline receives a high volume of calls from carers every day, as Julia Brown, Helpline Manager at PSPA explains: "Sadly by the time many carers come to us, they've already reached the point where they're struggling. People often don't want to look too far ahead. We do recommend trying to anticipate needs as much as possible, but I know this isn't always possible.

"When you're a carer and worn out, to talk about how you are struggling can be really hard. Many people feel it is wrong to say they are not coping. It's a barrier we are always trying to overcome. We say to everyone that asking for help is a sign of strength. Everyone needs help, especially if you are living with PSP or CBD.

"Timely referral for a carers' assessment is really important. But we know that carers' assessments like so many things are a postcode lottery. There are areas that do them quickly, but most people wait between eight to 12 weeks for an assessment. Then, if they are eligible for a care package they'll have to wait for a further eight to 12 weeks to have it provided. Care packages can make such a difference but social services are struggling. There is also a lack of paid care workers which is putting further pressure on the system."

## 2024 Awareness Campaign

Later this year, the UK will go to the polls for a General Election. Whoever forms the next government, it's vital that they improve support for carers of people living with PSP & CBD. So, this year, our Awareness Week campaign is all about showing #WeCare and calling on election candidates to commit to taking action to support carers.

PSPA is supporting calls made by Carers UK to:

- increase Carer's Allowance
- introduce a new payment for older carers
- give carers a legal right to respite breaks
- improve how carers are treated by our health and care system.

PSPA's Director of Policy and Influencing, Mark Jackson, said: "This year we're raising awareness of the incredible work that carers of people with PSP & CBD are doing up and down the country, but also of the challenges they face. PSPA wants to see carers put at the heart of reforms to the social care system. Carers need a better deal and we're not waiting until the next election to make that case – we want to let everybody who's standing in the General Election know about the issues that PSP & CBD carers face and ask them to commit to supporting carers if they're elected."

**"PSPA WANTS TO SEE CARERS  
PUT AT THE HEART OF REFORMS  
TO THE SOCIAL CARE SYSTEM.  
CARERS NEED A BETTER DEAL  
AND WE'RE NOT WAITING  
UNTIL THE ELECTION TO MAKE  
THAT CASE."**



# HOW YOU CAN HELP SHOW #WECARE THIS AWARENESS WEEK

You can help us show #WeCare by writing to your local election candidates to let them know about the challenges carers of people with PSP & CBD face and asking them to support a better deal for carers if they're elected this year. If you'd like, you can encourage your candidates to call or meet with you to hear more about your experiences.

You can find out who's standing for election in your local area and how to write to them on our website at [www.pspassociation.org.uk/awarenessweek-2024](http://www.pspassociation.org.uk/awarenessweek-2024) or by using the QR code at the bottom of the page. There's also a template letter you can download to get you started – but we encourage you to share your own personal experiences with your candidates!

We want to know if your candidates write back to you, so we can engage with them if they're elected to Parliament at the General Election – so please let us know at [communications@pspassociation.org.uk](mailto:communications@pspassociation.org.uk) or call us on 01327 322410.

## Invite your local candidates to a Support Group meeting

Coming along to a meeting will help the people who are standing for election in your area to learn more about PSP & CBD and how it affects the daily life of people that they're seeking to represent in Parliament – whether they're living with the condition, or they care for somebody who does.

By helping them understand the conditions and the issues you face, we can build backing among the next generation of MPs for better care and support for people living with PSP & CBD and their carers.

## Other Ways You Can Help

As well as writing to your local General Election candidates, there are several other ways you can help raise awareness of the importance of PSP & CBD carers in your community and show #WeCare this PSP & CBD Awareness Week.

### Take part in a Walk for Hope

As reported on our news pages, throughout summer, we are encouraging you to get out in your local community and take part in a Walk for Hope to raise awareness of PSP, CBD and of the incredible carers of people living with the conditions.

Our Walk for Hope is an awareness raising 5km walk or wheelchair push. You can take part in a local event (see events listed on our Awareness Map) or host your own walk with your friends, family and colleagues.

### Help us show #WeCare on Social media

Throughout PSP & CBD Awareness Week we'll be sharing stories on Facebook, Instagram and Twitter to highlight amazing carers of people living with PSP & CBD, the vital support they give to people living with the conditions and some of the challenges they face.

You can help us spread the word among your friends, family and community by sharing these stories on your own timelines and joining the conversation yourself by adding your photo to the social media template at [www.pspassociation.org.uk/awarenessweek-2024](http://www.pspassociation.org.uk/awarenessweek-2024) and sharing it on your timelines using the hashtag #WeCare.

### Share #WeCare with your local media

Help get more people talking about how #WeCare by talking to your local newspaper or radio station. Visit [www.pspassociation.org.uk/awarenessweek-2024](http://www.pspassociation.org.uk/awarenessweek-2024) to download a template press release with information about the campaign, that you can tailor with your own experiences or what you'll be doing to support PSP & CBD Awareness Week, and send it to your local newspaper or radio station.

### Let people know what you're doing locally on our Awareness Map

Whether you're contacting your local election candidates, taking part in a Walk for Hope or getting local media coverage for PSP & CBD Awareness Week, you can let us know what you're doing in your community to show #WeCare by adding it to our Awareness Map at [www.pspassociation.org.uk/awarenessweek-2024](http://www.pspassociation.org.uk/awarenessweek-2024)



HOW YOU CAN HELP SHOW #WECARE THIS AWARENESS WEEK

# "I WAITED SIX MONTHS FOR A CARER'S ASSESSMENT"

We often hear about the delays people face when seeking a diagnosis for the unexplained symptoms that develop. But what about accessing much needed support before or after a diagnosis?



DANNY AND CHRISTINE

Danny Snoek from Rochester, Kent shares his experience of delays to receiving support as a carer for his wife, Christine, who is living with PSP.

"In 2022, Christine's symptoms progressed and she began falling more frequently. You'd just suddenly hear a horrible thump and you couldn't rush there fast enough to find out how serious her fall was. Around the same time as her PSP diagnosis, she was also diagnosed with osteoporosis, so my biggest fear was Christine falling and breaking a bone and needing to be hospitalised. It was a very anxious and stressful time as I felt I couldn't leave her alone for more than half an hour or so.

"I was referred for a carer's assessment by the nurse practitioner at my GP surgery. It was three months before I had an acknowledgement of my application. You feel completely forgotten and worry if the process is working properly as you are not even sure you actually are on the list; then out of nowhere they ring and say they want to come around and see you. The visit took a further three months to happen, and that was supposedly being fast tracked due to Christine's symptoms worsening. So, it was six months wait in total.

"We do have family and friends locally, who come and sit with Christine for an hour or two so I can pop out. But I needed more support. Christine struggles to even

**"IT WAS A RELIEF WHEN FOLLOWING THE ASSESSMENT I WAS FINALLY TOLD I WAS ENTITLED TO RECEIVE NINE HOURS A WEEK SUPPORT."**

get around the house using a walking frame, and she is still at risk of falling backwards.

"For a few months, I ended up paying privately for a personal assistant (PA) for Christine. The support wasn't that great though. I didn't really feel she used her initiative and I had to keep telling her what to do, even to help with the obvious jobs around the house and the things Christine needed for her care.

"It was a relief when following the assessment, I was finally told I was entitled to receive nine hours a week support, which would give me some much-needed respite care. This new support came in the form of Emma, a council funded PA. They set up a direct payment system for me, which allows me to pay Emma directly when required.

"Emma is very helpful, and she has become a friend of ours now. She always asks what needs doing and offers to get me a meal ready if I have been out. The only thing she can't do is administer any medication but she does virtually all the household jobs that I would have to do.

"At the moment this level of support feels like enough. But I know the time will come when more support is needed. You see it at PSPA's Support Groups. They are a great source of company and information, but it was initially a shock to see people in the more advanced stages of the condition. This time, when things begin to change, I will be quicker at reaching out for help, knowing how long it took to receive a response the first time around."



# THE HEAVY LOAD OF CARING NOT ALWAYS RECOGNISED

Caring for a family member can be a really rewarding experience. At times it can also be extremely challenging and take its toll, physically and mentally.



Understanding how PSP & CBD impacts the whole family is important, as Christine Nunn from Ipswich has experienced whilst trying to get help for herself and her husband Chris, who is living with PSP.

Christine said: "Investigations into Chris' symptoms led to a diagnosis of Ataxia in 2019. Further tests over the next few years however led to a new diagnosis in February 2023 – PSP.

**"I DON'T THINK PEOPLE  
FULLY UNDERSTAND THE  
IMPACT PSP CAN HAVE  
ON YOUR LIVES."**

"It was a very worrying time, but our GP surgery has been pretty good. We were also referred to Dr Graham at Ipswich Hospital who organised support from the local hospice, a Parkinson's nurse and speech and language therapy.

"Chris took a real downturn in August and after a desperate call to the local community team their REACT team was sent in. For ten days, there was a flurry of activity, lots of different people coming and going. I didn't really know where I was, it was a lot to take in and sometimes they didn't give us warning before a visit, they just turned up.

"Despite feeling overwhelmed, the support was wonderful. They assessed the house; putting in rails and sending a commode, they sent nurses to watch Chris overnight (I was exhausted as he was getting up five or six times), and we were awarded some care support too. This was council funded for six weeks; half an hour in the morning to get Chris up and washed and then an odd couple of hours twice a week so I could get out and have a bit of time to myself.

"After those six weeks though, the council funding stopped. So, we've been self-funding ever since. I have reduced the care a little. It is currently enough, well enough with my support. I feel lucky I am quite able in myself.

"I wasn't going to apply for Carer's Allowance as reading up on it I didn't think I would qualify for this financial support. However, the REACT team asked someone to make contact to sort this out. The assessment was over the phone, around six weeks after the referral was made. I didn't hear anything then out of the blue I received a lovely letter saying I was entitled to carer's allowance and confirming how much I would receive. That was great to read, but in the next sentence it was all taken away, explaining since I was drawing my pension, I wouldn't receive anything. I had to read the letter several times to make sense of it. I still find this unbelievable.

"Overall, we're upbeat but occasionally it does all get on top of me. I felt quite low at Christmas. I did apply to a local counselling service but after completing a questionnaire and a short chat they advised I wasn't bad enough to warrant this support. I felt a bit unheard. I don't think people fully understand the impact PSP can have on your lives. People pop around and see Chris sat in a chair looking bright, but they don't see the full picture.

"My GP suggested a care home for respite care. But it meant I would have to organise and pay for this myself and getting dates for the respite tend to be a bit short notice. PSPA's Carer's Guide and Support Groups have been a great help. One lady I stay in touch with who lives in my area has recommended someone to give me some respite care at our house and I can book it in advance.

"I am grateful for the support we receive. I know others are far worse off. I do feel though that I have had to fight for everything we do have."

## OUR SUPPORT FOR CARERS

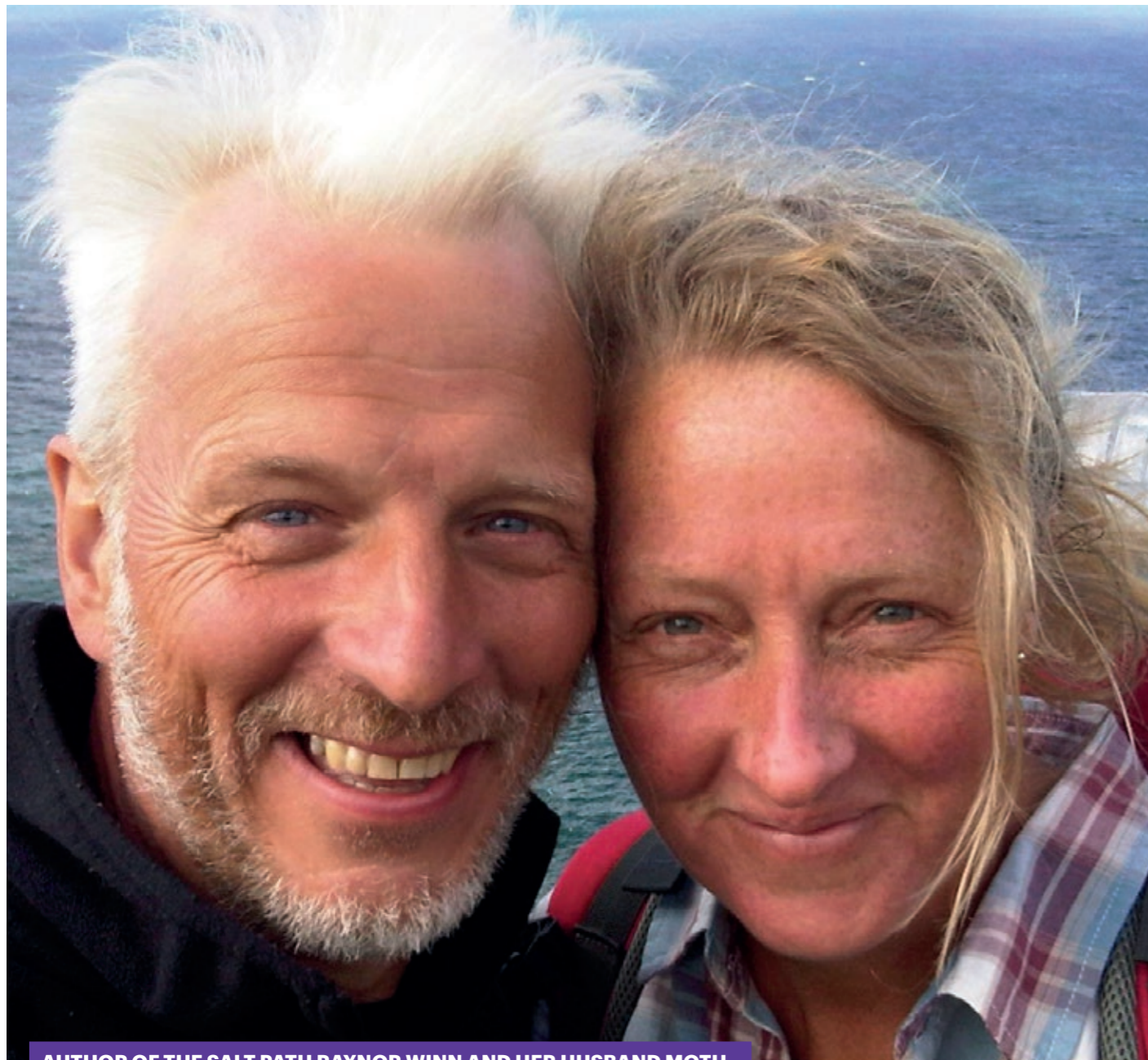
Caring for a loved one can be rewarding, but it can also be very tiring, putting a lot of demand on your emotional and physical wellbeing. We are here to support carers for people living with PSP & CBD in a number of ways.

- Our Helpline provides information, support and signposting. Contact the Helpline on 0300 0110 122
- A Carer's Guide to PSP & CBD resource outlining everything you need to know if you are caring for someone with either condition
- Our Link Volunteer Service provides short-term support to people affected by PSP & CBD to improve their wellbeing
- Carer's Support Groups and groups for men.



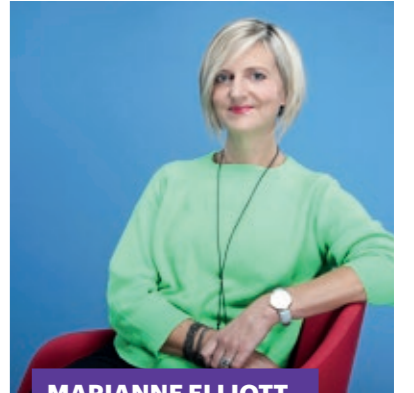
# THE SALT PATH FILM ADAPTATION INSPIRES HOPE

A book that's done so much for the PSP & CBD Community, that's inspired hope, endurance and encouraged many to take steps outside in nature has been adapted into a film, due to be released at the end of the year.



**AUTHOR OF THE SALT PATH RAYNOR WINN AND HER HUSBAND MOTH**

**"I SPOKE TO DOCTORS AS WELL AS PEOPLE LIVING WITH CBD AND THEIR CARERS. WHEN YOU'RE TELLING A TRUE STORY FEATURING AN ILLNESS, YOU HAVE A RESPONSIBILITY NOT JUST TO THE REAL LIFE CHARACTERS, BUT ALSO TO THOSE WHO ARE LIVING WITH IT."**



**MARIANNE ELLIOTT**

The Salt Path is Raynor Winn's beautiful memoir recounting the time when, in 2013, Raynor and her husband, Moth, lost their home and just days later were told Moth had CBD. Their world falling apart, they grabbed a tent and some sleeping bags, and set off from Minehead in Somerset to walk the 630-mile South West Coastal Path.

The Salt Path was published in 2018 where it spent 85 weeks on the *Sunday Times* Best Sellers List. PSPA Matters first spoke to Raynor in 2018, to share the book's message of hope with the CBD community.

Speaking back then Raynor said: "When we started walking, it was in a state of despair. We lost the house, and then Moth's diagnosis came in. It was just blow after blow. We had this idea that walking the path would give us time to form a plan, but it turned out not to be like that. It turned out to be about just putting one foot in front of the other, finding a reason to take the next step, a reason to go on. And ultimately, we became stronger as a result."

Marianne Elliott, the Tony Award and Olivier Award winning theatre artist, directed the film adaptation of *The Salt Path*. Starring Gillian Anderson and Jason Issacs, the film is due to be released later this year.

PSPA Matters spoke to Marianne about how the project came about. Marianne said: "I'd read *The Salt Path* on holiday and loved it. Then, a couple of years later, I was doing a show on Broadway when the pandemic closed theatre doors. Back home, I wondered if theatre would ever recover.

"I'd often flirted with the idea of directing a film, but never had the opportunity before because of the demands of theatre. It felt like this might be the time

to grab the opportunity. While walking, I remembered a very special book about walking. *The Salt Path* is an incredible story, very visual and perfect for film. I called film producer, Elizabeth Karlsen at Number 9 Films. Elizabeth looked into the rights to the book. She saw they'd already been bought by an American producer. She got in touch with them and they agreed to produce it together."

Ahead of filming, Marianne contacted PSPA as part of her research into CBD. Marianne said: "It's a small independent film. We didn't have a huge team of researchers and advisers. It was just me and the story. I felt a huge sense of responsibility to accurately portray CBD. I'd spent some time with Raynor and Moth, but I also wanted to get a sense of how CBD affected others to make sure the script and portrayal was right.

"I spoke to doctors as well as people living with CBD and their carers. When you're telling a true story featuring an illness, you have a responsibility not just to the real life characters, but also to those who are living with it. We also had to be very careful that while walking helped Moth maintain his wellbeing, we didn't want to be saying that if you walk, you will get better. We didn't want to create a film that was anti-scientific.



**The Salt Path was published in 2018 where it spent 85 weeks on the *Sunday Times* Best Sellers List.**



MOTH ON THE SALT PATH

“The script is quite sparing. In the book, Raynor and Moth don’t speak to each other much, apart from one incident when they’re pushed to. They were walking out their trauma in nature. We wanted to remain true to that. We never say in the film that walking helped Moth get better.”

Marianne, along with Gillian and Jason, visited Raynor and Moth in their home. “I remember Moth telling us that when he was diagnosed with CBD, he was advised to be careful going up and down the stairs. Instead, he went the other way entirely. Moth is very fond of nature and being in a natural environment felt beneficial to him.”

PSPA arranged for Marianne to attend a number of online CBD support meetings and set up calls with people living with CBD and their carers. Marianne said: “From those conversations, I learned how CBD strikes people in different ways. I heard how hard the path to diagnosis was, and how difficult it is to come to terms with getting diagnosed with a condition that has no treatment, no cure. I’m grateful to everyone for sharing their experiences of CBD so openly with me. I hope we can help in some way, shine a light on this little known and little understood condition.”



BRIAN JOHNSON

Brian Johnson, who is living with CBD shared his experience of receiving a diagnosis with Marianne. Brian said: “I explained how I’d been diagnosed with Parkinson’s, but my doctor said he wanted to change it to CBD. It was devastating.

“I’d never heard of The Salt Path. What an incredible story, and it really highlights the importance of getting out. That’s something I try to do on my electric scooter as much as possible. I’m really pleased this film is happening. I hope it encourages people with CBD to do their best to live as positively as they can. I also hope it raises awareness of CBD. We need more funding for research and we need it to have a greater profile so that people can get better care.”

Stephen A’Court is a carer to his wife Elaine, who is living with CBD. Like Brian, Stephen also shared his and Elaine’s experiences of CBD with Marianne. Stephen said: “We’ve had such a lot of help from PSPA, so when they asked if I’d be willing to share our experiences of CBD with the film director I was very happy to do so.

“I talked about Elaine’s progression and her symptoms, including the lengthy path to diagnosis. The director was very interested in understanding how Elaine managed daily life, and her interactions with other therapists. It was clear the filmmakers wanted to portray CBD as accurately as possible.”

After the interview, Stephen read all three of Raynor Winn’s books. He was really struck by the power of walking, and spending time outdoors. Stephen said: “Since Elaine moved into a care home she has further deteriorated. Visiting her was challenging, she is non-verbal and her cognition is impaired, so it’s hard to keep up a one sided conversation for any length of time. But, she can still walk. So, inspired by The Salt Path, we now go out for walks around the park adjacent to the care home. It’s so much nicer than sitting in the lounge area in silence. We enjoy the flowers, the ducks and swans on the lake, the pram pushers and the dog walkers. It gives us something nice to focus on together.”



STEPHEN A’COURT

**“WE’VE HAD SUCH A LOT OF HELP FROM PSPA, SO WHEN THEY ASKED IF I’D BE WILLING TO SHARE OUR EXPERIENCES OF CBD WITH THE FILM DIRECTOR I WAS VERY HAPPY TO DO SO.”**





## DAVID TAKES ON SOUTH WEST COAST PATH CHALLENGE INSPIRED BY THE SALT PATH

David Carter, 58, from Bicester, is walking the South West Coast Path to help raise awareness of PSP in memory of his wife Linda, who died of the condition in October 2023.

**"BEING SO INSPIRED, I SET MYSELF THE CHALLENGE TO WALK THE WHOLE OF THE SOUTH WEST COASTAL PATH THIS YEAR."**



DAVID CARTER

The army veteran started his walk on 16 April in Minehead and aims to complete the 630 miles walk in just 58 days. David said: "I lost Linda, my partner and best friend of over 21 years, from PSP. Due to the impact of the condition, I cared for Linda full-time for the last two or three years of her life.

"Whilst adjusting to living alone, I read the book called The Salt Path over Christmas, and I was inspired so much by the couple's story. Moth has been diagnosed with CBD which is closely related to PSP.

"Being so inspired, I set myself the challenge to walk the whole of the South West Coast Path this year. I started my walk on 16 April in Minehead, and aim to finish in Poole on 12 June - the day before my 59th birthday.

"I experience chronic lower back pain as a result of my previous 20-year military career so I will need to arrange for my overnight equipment to be transported between campsites. However, I will still carry some supplies as I walk. This will very much be a pilgrimage for me and I'm under no illusion about the challenges I'll face both physically and emotionally as I attempt to complete the walk.

"I've been training hard and I'm building up my strength so I can complete the 630 miles distance. It felt good to focus on something positive after the heartbreak of losing Linda. I want to support PSPA and raise money to invest in supporting others living with the condition as well as funding research into future treatments. I hope that friends and members of PSPA Support Groups located close to the route will be able to join me for various sections."

## "READING THE SALT PATH I FINALLY KNEW WHAT I HAD"

Last year in PSPA Matters we shared the story of how Beth Shephard-Walwyn and her husband Hugh walked the South West Coast Path.



BETH AND HUGH



Starting in Minehead, Beth and Hugh started to walk the path in 2013, doing a few days each trip. By the time the couple got to Penzance in 2018, they noticed Beth was slowing down.

Beth, like most people living with CBD, I had numerous appointments with various professionals but no confirmed diagnosis until 2020. By then, Beth had already started to put the pieces together of what she may have by going back to The Salt Path.

Beth said: "I'd asked my daughter for The Salt Path for my birthday a few years ago and thoroughly enjoyed it. As Hugh and I were back on the South West Coast Path, I suddenly remembered that Moth in the book had a neurological condition. When we got home, I picked up the book and noticed a number of similarities. That's when the penny dropped that, like Moth, I too had CBD."

Hugh said: "By the time we completed the coastal path, Beth had received her diagnosis of CBD. Having read the book, it's helped Beth to understand her symptoms and has given us hope in how to help manage them.

"We've always been keen walkers and we were determined to walk to help maintain her wellbeing. Both of us think it's helped Beth. We were walking around 10 miles a day. Recently that has dropped to around seven, but Beth is doing well and never has any falls or stumbles. When Beth does get poorly and is unable to walk, we notice how it affects her. When she gets back on her feet, she appears to improve and her sleep is much better."

Beth and Hugh were part of a group of people with CBD and their carers who met with film director Marianne Elliott. Hugh said: "It was nice to meet as a group and hear other people's experience of CBD. The book had such a big impact on us and on Beth understanding her condition, so we were keen to be involved in helping the film in any way we could."

Beth said: "I spoke to Marianne for quite a while about my symptoms and how long it took to get a diagnosis. It was clear it was very important to her that CBD was accurately portrayed. We're looking forward to watching the film when it's released. In the meantime, we've started to walk the Wales Coast Path."



# CONTINUING TO SHINE A LIGHT ON PSP & CBD

Earlier diagnosis, increased research funding, better care, reduced isolation and access to more support are all compelling reasons to raise awareness. That's why raising awareness is a key part of our strategy.

We know increased awareness is our path towards a better future for everyone affected by PSP & CBD. Through media activity, building relationships with MPs and policy makers, and developing partnerships with other organisations, we seek to find ways to build awareness.

Over the past few years we have run numerous campaigns to shine a light on PSP & CBD - Ed's Laces, Swallow, It's Not Parkinson's, Unmute, and of course our Red Flags. Since our PSP Red Flag poster campaign in 2016, the Red Flags have gone on to become a key part of our awareness raising activity.

The Red Flag poster details 10 symptoms to help aid diagnosis of PSP and speed up referrals to neurologists. Over 6,500 posters have been handed to GPs, nurses and therapists across the UK, while 8,000 people have visited our Red Flag page on the website.

Following feedback from GPs on how useful the Red Flags are and also feedback from volunteers about how helpful it is to have something like this to distribute, last year we created our first Eye Red Flag poster for opticians. Almost 1,000 Eye Red Flags have been shared with opticians to alert them to signs of PSP. We hope to grow this number over the coming months.

Alongside our focus for this year's Awareness Week on unpaid carers, distributing Red Flags to GPs and Eye Red Flags to opticians forms part of our ongoing activity to ensure those best placed to make a difference to people living with PSP & CBD are supported to do so.

**OVER 6,500 POSTERS HAVE BEEN HANDED TO GPs, NURSES AND THERAPISTS ACROSS THE UK.**



**MORE INFO**

If you would like to share our Eye Red Flag with opticians or our Red Flags posters with GPs please visit [www.pspassociation.org.uk/information-and-support/awareness-tools/](http://www.pspassociation.org.uk/information-and-support/awareness-tools/)

# "I STRUCK GOLD THAT DAY"

An opportune moment visiting her local opticians last year provided the perfect chance for Louisa Roberts-West to support last year's awareness campaign aimed opticians.



TRISH WITH LOUISA, PSPA VOLUNTEER

**"MUM DIED FROM PSP WHEN SHE WAS 66. AS A FAMILY WE FOUND IT VERY HARD TO LIVE WITH SUCH A DEVASTATING CONDITION THAT NO ONE HAD HEARD OF."**

It was a real moment. We hugged. No more words were needed, we had both felt the devastation caused by PSP.

"I showed Trish the Eye Red Flag posters and explained our desire to alert opticians to early eye symptoms and what should be done if these symptoms are spotted. Trish spoke to her boss about this initiative and how they could get involved in the campaign. Soon afterwards all 10 branches of Rawlings confirmed they would display the posters and that all their opticians will be told about the signs to look out for.

"Rawlings also posted a blog about PSP & CBD on its website. This shows the power of just one conversation and how the ripple effect can spread to expand awareness beyond your expectations. Trish has since come along to our Support Group in Hampshire. It felt like we were meant to meet.

"Raising awareness is important to me. Mum died from PSP when she was 66. As a family we found it very hard to live with such a devastating condition that no one had heard of. It was incredibly isolating. That's why it was so important for me to set up a support group, to create a community to limit the isolation often felt with having a rare disease.

"Whenever I go to the GP surgery I take leaflets, and I often share information on social media. Over the years I've done radio interviews and been in the local paper. But it's worth remembering that even just having a conversation with someone who didn't know about PSP is helping. You never know where it might lead."

Armed with the Eye Red Flag posters listing specific eye symptoms for opticians to look out for, Louisa set out to raise awareness. On this particular morning, it actually went much further than Louisa expected.

Louisa said: "It's incredible what one conversation can lead to. As I walked through the doors of Rawlings Opticians on our local high street that day I struck gold. As fate would have it that one action created so much awareness about PSP & CBD.

"I went up to the desk and asked the lady if I could talk to her about PSP, but before I got to the second 'P' this lady finished the sentence for me. She told me her name was Trish and that her mum had died from PSP.



## OUR STRENGTH IN NUMBERS

Our strength comes from the power of our PSP & CBD community and the action this community takes to improve the care and support for everyone affected.



To boost the efforts of our PSP & CBD community, last year we launched our new Awareness Raising Grants. These grants are to help harness the ideas, skills and experiences of people living with PSP or CBD, health and social care professionals, volunteers and supporters to raise awareness in their communities.

Last year two grants were awarded to health professionals. Dr Boyd Ghosh, Consultant Neurologist in the Wessex Neurological Centre in Southampton, was awarded a grant to set up online 'Network multidisciplinary meetings' in Wessex for all health professionals in the region.

Therapists and doctors working in the community now have a place where they can discuss cases and establish a management plan, in conjunction with Boyd's team from the specialist clinic. These meetings provide community teams access to specialist information to inform the care they deliver to their patients with PSP & CBD. Alongside the meetings, there is also training targeted at specific areas, such as physiotherapy, occupational therapy or speech and language therapy.

Advanced Orthoptist Dominic Burdon from the Royal Eye Infirmary, was also awarded a grant to raise awareness to improve diagnosis of PSP in professionals who assess eye movements. The team at the Plymouth Ocular Motility Unit have assessed if their eye movement assessment procedure identified early signs of PSP, and how individual tests from 17 people with PSP influenced the patients diagnosis.



Talking about the study Dominic said: "The grant from PSPA has now enabled us to commence our audit study on our experience with PSP patients. The aim of this project is to raise awareness for how clinicians can effectively test for the characteristic ocular signs of PSP, so that PSP clinical diagnosis is as swift and efficient as possible. Case data collection has now been completed and we are analysing the data and writing it up."

The results from this study will be compared to current diagnostic guidelines relating to PSP eye movements. By publishing these findings, it's hoped other professionals who do not regularly see patients with PSP will be more confident in referring patients to the unit.

While these grants were awarded to healthcare professionals, our grants are open to anyone who has a good idea for a project focused on raising awareness. This year we have £8,000 to award. There are two levels of awards, those at £1,000 or under, and awards between £1,000 to £4,000.

**FOR MORE INFORMATION ON THE GRANTS AND GRANT CRITERIA - VISIT**

[www.pspassociation.org.uk/news/how-you-can-apply-for-a-pspa-awareness-grant/](http://www.pspassociation.org.uk/news/how-you-can-apply-for-a-pspa-awareness-grant/)

**The deadline for applications is midnight Wednesday 31 July 2024.**

## MEET MARK

To grow our campaigning and influencing work to improve care and support for people living with PSP & CBD, PSPA has recruited its first Director of Policy and Influencing, Mark Jackson.



Before coming to PSPA, Mark was a Senior Policy and Research Manager at Marie Curie, where his work focused on financial security for people at the end of life. Mark led Marie Curie's successful #Scrap6Months campaign to improve access to fast-tracked benefits for terminally ill people. Now he is turning his attention to PSP & CBD, as he explains in his own words here.

"I'm just a short time into my role but already I'm struck by how much impact such a small charity has. PSPA is small but it is certainly agile. It is also very close to the people it exists to support and that is very important to me.

"Even though there hasn't been a dedicated policy and campaigning function, it's incredible to hear about so many PSPA volunteers raising awareness among GPs and opticians, and for being so involved in our awareness campaigns. I hope to build on this great work. Already I can see so much opportunity for us all to unite around campaigns that will have lasting impact on those living with PSP & CBD.

"To drive forward research, to improve diagnosis, to ensure people have access to the latest treatments and to make the incurable curable, we need to

campaign. When campaigns are successful it has a huge impact on people's lives. In my last role, successful campaigns meant people living with a terminal condition didn't have the burden of going through multiple assessments or experience delays in accessing benefits. It helped ease the financial pressure for people.

"Clearly there is a significant problem in people with PSP & CBD getting an accurate and timely diagnosis. There are not enough neurologists. Not enough money is invested in research. People with PSP & CBD are not all getting access to services quick enough. And carers are left with little recognition or support. We have a lot to work through to make lives better for people living with the condition today.

"With a General Election coming up this is a very good year for us to build new relationships with a political audience. Whoever forms the next Government will have to reform the social care system. As part of this reform, the value of unpaid carers must be considered along with how the system can best support them. This gives us an opportunity to build relationships with potential MPs while they're still parliamentary candidates. At the moment I'm developing our awareness campaign that will ask people to contact their parliamentary candidates about the vital role of unpaid carers (see page 15).

"I want to be accessible to people and would welcome anyone from our PSP & CBD community to get in touch to say hello, or share a problem they are facing. I'm looking forward to working with the PSP & CBD community to drive change in both care and research funding.

"I will also be working with the team to build awareness of PSP & CBD. We must raise awareness to give both conditions greater prominence in the media, homes, hospitals, laboratories and government buildings. It will take collaboration to achieve our goals, but with the determination and dedication I've already seen from the PSP & CBD community, I know we will get there."



# "MUM'S EXPERIENCE OF PSP MADE ME PASSIONATE ABOUT RAISING AWARENESS"

Denise Hunt's mum Joyce, first started showing symptoms of PSP in 2014. The backwards falls, fixed eyes, changes in mood and personality became progressively worse, yet it took over four years for a diagnosis of PSP to be confirmed. In that time Denise accompanied her mum to numerous appointments and supported her through two unnecessary surgeries.



LEFT TO RIGHT ALISON STAPLES, DENISE'S MUM JOYCE, AND DENISE



JOYCE WITH HER GRANDDAUGHTER CATHERINE

Having first-hand experience of how little health professionals know about PSP, Denise became an education volunteer for PSPA, where she raises awareness with those best placed to make a difference for people living with both PSP & CBD.

Denise said: "Having seen what Mum went through, I'm passionate about raising awareness. Looking back I can't believe she had two surgeries and so many appointments that were entirely unnecessary. What was the cost of this to the NHS? And of course after every appointment there would be a referral to another part of the NHS, and that would mean another six month wait. It was frustrating for the family. We saw all these strange symptoms but we had no answer.

"An earlier diagnosis would have benefited Mum and the rest of the family. While there are no treatments, there is still a lot that can be done to enable people with PSP & CBD to live as well as possible. Mum could have had physiotherapy to help her maintain her mobility and comfort for as long as possible. She could have had mental health support to improve her wellbeing. These are all things she was deprived of.

"With hindsight I think I should have pushed for more. But I was overwhelmed and it's hard when what you're hearing from the consultant is that there's nothing more that can be done. I know now that's not true.

**"MUM HAD A LONG PATH TO DIAGNOSIS, BUT AS AN EDUCATION VOLUNTEER, I'LL DO WHATEVER I CAN TO SPEED THIS UP FOR OTHERS."**

"Her diagnosis finally came following a bad fall that landed her in hospital, where she remained for six weeks. Mum went straight from the hospital into a care home. She never returned to her own home. Never had the ability to go through her things, to pack, or to see her home one last time. After Mum died I discovered a notebook in her room. She'd written poems and little notes like 'I must keep my brain active, I am fighting this'.

"As an education volunteer I want to prevent families from going through what we did. It can be difficult to get in front of GPs, but when we do, the feedback is always so positive. My talks to GPs differ from the talks I do at care homes. With GPs I focus on the symptoms and the importance of referring them to a neurologist. With care homes, people will already have their diagnosis, so I talk about their risks of falls, or why they may act odd, and most of all, as a family member, what care I would like my loved one to get.

"I split my talks into focusing the first half on our family story and all the unnecessary appointments and interventions Mum had, and in the second half I talk about the symptoms and how they differ from Parkinson's symptoms, using PSPA's Red Flags. At every talk I ask the GPs to think about one or two patients they've seen who they now wonder if it might not have been Parkinson's but PSP or CBD. There's always one or two who say there is.

"Even though a diagnosis of PSP & CBD won't lead to a cure, it gives the family the ability to do nice things together and make some special memories. But, when you are waiting for a diagnosis that becomes the focus instead.

"The last couple of GP education sessions have been online. I did one recently with another education volunteer in a different area to me, Val Wallace. There were about 30 trainee GPs there. They were really responsive to our session. Val had done so well to set up the meeting and that we were able to speak to so many trainee GPs in one session.

"Along with raising awareness among GPs, I also want to focus on opticians. I remember having such strange conversations with Mum's opticians. He should have spotted her eyes were fixed, but this was missed. Opticians can play such an important part in enabling people to get quicker diagnoses.

"I'm pleased to be able to do something to help. Volunteering in this way makes me feel that I can have an impact on the care people in the future receive. That's what keeps me going. I really want to ramp up my work in this area and do as much as I can do, while also having a full time job. I've set myself some goals for this year including getting in front of more opticians. Mum had a long path to diagnosis, but as an education volunteer I'll do whatever I can to speed this up for others."

## Denise's tips for getting in front of GPs

- All GPs have an education faculty in their local area. Search online to find a contact and get in touch. They may have a neurology day in the diary that you can ask if PSP & CBD can be covered.
- For a more direct approach, contact the GP surgery Practice Manager. Many will hold educational sessions during lunch, so it's worth asking them to do one on PSP & CBD.
- If you live near a medical school this is a great way to try and get in front of trainee GPs.

## CONTACT US

If you would like to become an education volunteer for PSPA please contact our volunteering team on **01327 356137** or **volunteering@pspassociation.org.uk**



# CREATING A BETTER FUTURE – ONE YEAR ON

**OUR PURPOSE IS TO  
CREATE A BETTER  
FUTURE FOR  
EVERYONE AFFECTED  
BY PSP & CBD.**

Back in April 2023 we set out a new three year strategy detailing our goals and priorities to help create a better future for everyone affected by PSP & CBD. Through PSPA Matters, we want to continue to share with you the progress we are making.

Explaining the goals of PSPA, Rebecca Packwood, Chief Executive said. “We want to make advances in the diagnosis and get it right early. We want national standards of care so if someone has a PSP or CBD diagnosis they know what care they should be getting. We also want to make sure everyone who gets a diagnosis knows we exist because the more people we support the better we can help research to make advances, like those we have seen in other neurological conditions.

“There are no treatments, there is no cure so we need to continue to invest in research to make sure the condition is better understood and that trials for treatments take place. Our mission is to make this situation better whether that’s research for the long-term or quality of life for right now.”



## SUPPORT & INFORMATION

Enabling people to live the best life possible



## RESEARCH & AWARENESS RAISING

Improving quality of life



## INVOLVEMENT

Putting people living with PSP & CBD at the heart of what we do

One year on from the launch of our strategy, this is what we achieved in 2023...

## 1 ENABLE PEOPLE WITH PSP & CBD AND THEIR FAMILIES TO LIVE THEIR BEST LIVES POSSIBLE WITH HIGH QUALITY SUPPORT AND INFORMATION.

- Five new support groups taking the total number to 33 support groups across the UK
- Launched a new online carers group for men
- We developed and distributed 424 'A Carer's Guide to PSP & CBD' leaflets
- Funded a support grant or provided access to voice banking for 128 people
- 10,334 contacts were made with the Helpline (via phone or email) enabling people to access vital support and information
- Registered 1,258 new joiners who have PSP, CBD or are carers or family members.

## 2 IMPROVE THE QUALITY OF LIFE OF PEOPLE LIVING WITH PSP & CBD THROUGH RESEARCH, EDUCATION AND AWARENESS RAISING.

- Provided training and study days for 848 healthcare professionals
- Distributed 1,454 publications to health and social care professionals
- Hosted a worldwide research symposium on PSP & CBD for 250 of the world’s leading researchers
- Created a new Director of Policy and Influencing role to lead on our work to raise awareness and secure policy change to benefit all those affected by PSP & CBD
- Awarded five new research grants with a total value of £152,163
- Invested £285,000 in a new research fellowship to continue our commitment to developing research leaders for the future
- Distributed more than 800 Eye Red Flag posters to opticians during the 2023 awareness week.

## 3 PUT PEOPLE LIVING WITH PSP OR CBD AT THE HEART OF WHAT WE DO.

- Set up a services committee made up of people affected by PSP or CBD and health and social care professionals. The committee has designed an evaluation of the carers group to measure impact and effectiveness
- Created a patient involvement in research group that meets monthly. The group have taken part in consultations with pharmaceutical companies to advice on trial protocols and helped to design the research information day
- Focus groups have helped with the redesign of parts of the website
- Launched our 30th Anniversary Awards to thank and celebrate the PSP & CBD community.



# CELEBRATING 30 YEARS OF PSPA

On Wednesday, 27 March we hosted an evening 30th Anniversary celebration in London.

More than 80 PSPA supporters joined us on Threadneedle Street to look back at the charity's achievements over the past three decades, before setting out our ambitious plans for the future. As Chief Executive, Rebecca Packwood, explains these plans will involve working for fast and accurate diagnosis of PSP & CBD, immediate treatment and consistent care.

As well as hearing from Rebecca, the attendees, who ranged from PSPA volunteers, fundraisers, healthcare professionals and families we've supported, also watched a video message from Professor James Rowe sharing progress being made in research. In addition, PSPA Trustee Paul Innes held a Q&A session with supporter Kelly Hooper, who not only helped organise the venue for the celebration, but also shared her own personal experience of PSP and how it has inspired her to take on 30 challenges for PSPA during 2024.

Family members of PSPA Founder Michael Koe helped cut the two anniversary cakes, one of which was made by one of PSPA's first employees, Debbie Benadie, and the other of which was designed by volunteer Eram Osman.

After the cake cutting attendees shared heartfelt experiences and were tasked with pledging to complete 30 themed challenges of their own during PSPA's milestone year. Two adventurous fundraisers, David Carter and Michael Aquilina spoke about their big 2024 challenges: a South West Coast Path trek and a London to Vietnam cycle, both which began this April.

Rebecca said: "Our celebration event was a wonderful evening filled with shared experiences and a drive to make things better for people affected with PSP & CBD, now and in the future."

"It was a pleasure to catch up with longstanding and new supporters during the evening and we are excited about what the rest of our 30th Anniversary year will bring. Thank you to everyone who attended the event. We very much appreciate the ongoing support from our loyal followers, who make our important work possible."



**THANK YOU TO EVERYONE WHO ATTENDED THE EVENT. WE VERY MUCH APPRECIATE THE ONGOING SUPPORT FROM OUR LOYAL FOLLOWERS, WHO MAKE OUR IMPORTANT WORK POSSIBLE.**



# "WITH A DISEASE THAT TAKES AWAY SO MUCH, IT FEELS GOOD TO BE ABLE TO FIGHT AGAINST IT"

Gilda Thornton's happy life was turned upside down by a diagnosis of CBD. Since then, Gilda has become focused on raising awareness. Gilda already has a number of media interviews under her belt. Here, she shares why sharing her story is so important to her in her own words.



**"I'M PASSIONATE ABOUT RAISING AWARENESS BECAUSE SO LITTLE IS KNOWN OR UNDERSTOOD ABOUT CBD. WITH MORE AWARENESS THERE WOULD BE BETTER AND EARLIER DIAGNOSES, MEANING PEOPLE WOULDN'T BE LEFT IN LIMBO LIKE MOST OF US."**

"In a little room on a random day my world collapsed. CBD. Three letters I'd never heard of. Three letters that would take away so much of what I enjoyed, that would take away so much of what made me me.

"For three years I knew something was wrong. My touch typing had got a lot slower and I was losing function in my right arm. I'd previously had breast cancer and was worried the cancer was returning.

"First I struggled with zips, next I couldn't do buttons. I couldn't type and I couldn't write. The list of things I was no longer able to do was getting bigger, as was my growing frustration. For so long I had no idea what was going on. It was hard to be in limbo with no answers.

"My GP said I needed to see a consultant and that I'd be better off going private because the waiting list was 12 months long. After many meetings, over the course of six months my neurologist finally told me I had CBD. The neurologist was very kind and carefully explained the condition to me and my husband Gary. But it was hard to take it all in. After the appointment Gary and I walked silently to the car.

"My husband and two children searched the internet to find out as much as they could. There was no treatment, no encouraging reading that gave us hope of me being able to get rid of this horrible condition. But their research led them to PSPA, and we are so grateful it did.

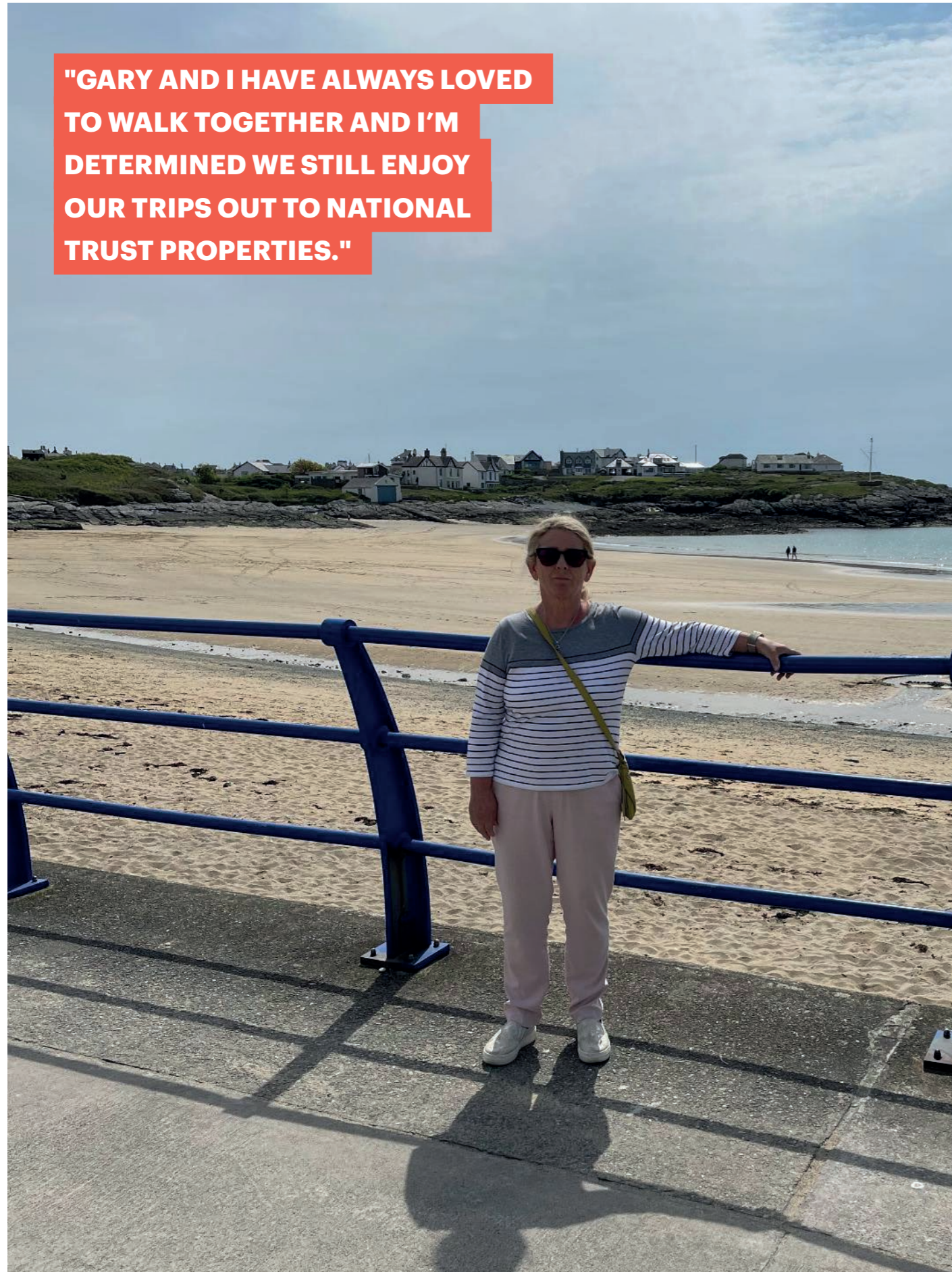
"PSPA has been such a source of support in these scary and confusing times. PSPA gave me a grant so

that I could bank my voice for the future. It felt like a positive step to take and is one way I can stop CBD from taking my voice and my identity away from me. PSPA also helped me to understand the benefits I'd be entitled to, and signposted me to other sources of help.

"I worked with domestic abuse survivors for many years supporting them move on with their life. I was very passionate about my work. I've seen how people can rise up after traumatic experiences. I think this has helped me to come to terms with my diagnosis. I start everyday feeling as positive and hopeful as I can do. It helps that I have my husband Gary by my side.

"Attending monthly PSPA Support Group meetings with other people living with CBD has been such a help to me. I learn so much from the group and we use What's App to keep in touch in-between the meetings. All this means I don't feel alone. I feel like I'm part of a lovely community of people. Of course, it's a community no one wants to join, but I'm relieved it exists.

"I'm passionate about raising awareness because so little is known or understood about CBD. With more awareness there would be better and earlier diagnoses, meaning people wouldn't be left in limbo like most of us. So many at the Support Group had been misdiagnosed with Parkinson's, in fact some of them have lived with the wrong diagnosis for as much as five years.



"GARY AND I HAVE ALWAYS LOVED TO WALK TOGETHER AND I'M DETERMINED WE STILL ENJOY OUR TRIPS OUT TO NATIONAL TRUST PROPERTIES."



"Raising awareness makes me feel like I'm making a difference. With a disease that takes away so much it feels positive to feel able to fight against it. I've been on local BBC radio and PSPA's podcast to talk about CBD. After the BBC interview I was inundated with phone calls and kind messages. It was such a lovely feeling and it's motivated me to do more.

"Most healthcare professionals I've come into contact with have never heard of CBD. GPs, nurse practitioners and hospital staff don't know what it is. It's really frustrating. I try to do what I can to help change things. Whenever I go to the opticians I bring leaflets with me and ask them to share them with the staff.

"I've had to give up driving, I can't walk unaided, I no longer do yoga or go to the gym. It's been a big adjustment for me. To go from the person who organised everything – the house, the cooking, washing and ironing to not being able to do anything physical. But my motto is 'if you don't use it you lose it' so I'm determined to keep pushing on and doing whatever I can to stay independent. Gary and I have always loved to walk together and I'm determined we still enjoy our trips out to National Trust properties.

"Contributing to research is the other way I feel like I can make a difference. I travel to UCL to take part in the PROSPECT study. I've given blood and tissue samples, had lumbar punctures and cognitive tests. After a day at the clinic I'm totally washed out by the time we get home, but despite the exhaustion it's very rewarding to be part of something like PROSPECT.

"While I prefer to focus on what I can do, at the same time I have to accept the realities of the condition. We try to plan ahead as much as we can. We recently moved into a bungalow and will be soon having a wet room fitted. I also have lots of equipment to make me more comfortable at home. The information and support we've got from PSPA has really helped us to feel prepared for each stage of the condition.

"My husband says he is proud of me but I'm also very proud of him. He raised over £1,000 by taking on a 20-mile walk for PSPA. I'm the one who has CBD, but we are both living with it and we will continue to fight it together.





# INSIDE NEUROLOGY: OUR UNIQUE BRAIN

PSPA joined forces with The Brain Charity and ITN Business to create a programme highlighting PSP & CBD to raise awareness of both conditions. The programme features Bruce who is living with CBD and his wife Neda.



Before CBD, Bruce was an active and sporty graphic designer who enjoyed a busy family life with Neda and their two children. Then worrying symptoms started to appear including difficulty speaking and writing, apathy, social anxiety and balance problems.

Bruce was filmed at home where he shared his frustration of having to wait five years for a diagnosis. In the film Bruce said: "It's been a long journey. Five years. Very frustrating." Neda went on to explain how the five year wait for a diagnosis delayed support that would have benefited Bruce.

Neda said: "One of the big downsides to this five-year delay is that had we realised physiotherapy, speech and language therapy, exercise and walking would

have all benefited Bruce. The system doesn't kick in until you have a diagnosis, nor does the funding."

PSPA's Chief Executive, Rebecca Packwood and neurologist and PSPA Trustee Dr Boyd Ghosh, also feature to discuss delays in diagnosis and accessing essential support and care. Rebecca Packwood said: "As rare conditions, PSP & CBD are relatively unheard of even among the healthcare community. So, the programme is an amazing opportunity to not only highlight the conditions and how they can impact on family life. But also, the challenges people like Bruce and Neda, face in terms of getting a diagnosis and accessing relevant support and care. We hope the programme helps raise awareness of the conditions and also how PSPA can help."

**"THE FIVE-YEAR DELAY FOR BRUCE GETTING HIS CBD DIAGNOSIS TOOK ITS TOLL ON OUR FAMILY AND WE WANTED TO DO WHATEVER WE COULD TO HELP REDUCE THIS FOR OTHERS."**



Speaking about why they wanted to be part of the ITN film Neda said: "It was wonderful to meet the PSPA team and so many other lovely PSP & CBD families at the PSPA Family and Friends Day in Windsor. The meeting really crystallised how tirelessly the PSPA team are working to support all of us. From simple advice to signposting and guidance on what services and benefits are available, to small grants and a huge emphasis on raising funds to support scientific research.

"Bruce, our children Lila and Daria, and I felt that we would like to give back in whatever way we can. So, when PSPA contacted us about the ITN Business Inside Neurology film aimed at bringing awareness to PSP & CBD, we were more than happy to take part.

"The five-year delay for Bruce getting his CBD diagnosis took its toll on our family and we wanted to do whatever we could to help reduce this for others. If by sharing the film we can spread awareness of the symptoms associated with these rare atypical parkinsonian conditions then we will empower others to help themselves, in partnership with their doctors to reach a diagnosis sooner."

## SEE THE FILM

The film so far has been viewed more than 340,000 times.

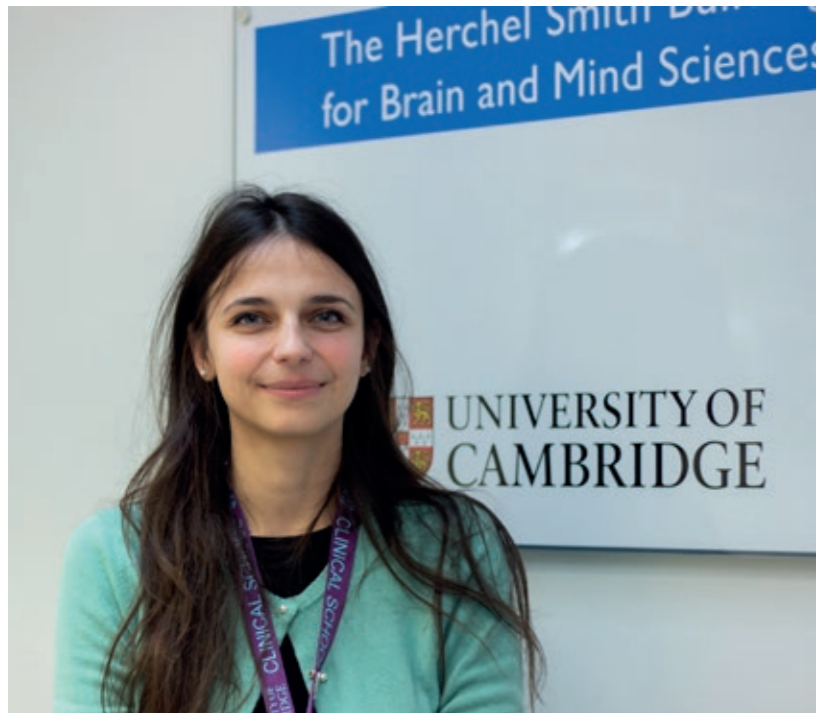
To see the film, scan the QR code below or go to <https://business.itn.co.uk/programmes/inside-neurology-our-unique-brain/> or [www.youtube.com/channel/UCGRa4ufS\\_i4eu6SGuB8Ni6Q](https://www.youtube.com/channel/UCGRa4ufS_i4eu6SGuB8Ni6Q)





# AWARENESS DRIVES RESEARCH

Dr Maura Malpetti is a research fellow at the Cambridge Centre for Frontotemporal Dementia and Related Disorders, where she is studying biomarkers that show inflammation in the brain.



Before securing her fellowship Maura was a PhD student at the centre, studying the application of brain scans (or neuroimaging techniques) to investigate inflammation and junk proteins in the brains of people with PSP, CBD and frontotemporal dementia.

Maura recently published two research papers showing that profiles of inflammation can be measured in blood of people living with PSP & CBD. Inflammation signatures in the blood are related to inflammation in the brain and clinical progression. This will aid earlier detection of changes in the immune system and will help predict the likely speed of progression of the disease in individual patients. Here, Maura shares why it's so important scientists share their results as early as possible and why awareness of research among people living with the condition is so vital to finding a cure.

"When I was studying for my Bachelor's and Master's degrees in Milan, I learned about neurodegenerative

disorders and the progressive damage they caused to cells and the nervous system. I was shocked that people knew so little about these devastating conditions. Far too much was unknown to be able to arrive at a cure. From this moment I knew I wanted to focus my career in this little understood area.

"The work Professor James Rowe and his colleagues in Cambridge were publishing really struck me. I was interested in his multidisciplinary approach to PSP & CBD, with both clinicians and non-clinicians working and learning together. One of the most compelling aspects for me was how close his research was to people living with the conditions. How he would see them in clinic and how his clinic would straddle the two areas of care and research so well.

"It was a privilege to join Professor Rowe's team at Cambridge as a PhD student looking at brain scans to see what was happening in the brains of people with PSP & CBD. PET and MRI scans are very valuable

**"THOSE LIVING WITH PSP & CBD ARE A VITAL PART OF THE PUZZLE TO SOLVING THIS COMPLICATED PROBLEM. THEIR INVOLVEMENT IN RESEARCH STRENGTHENS AND ACCELERATES IT."**

tools to enable us to track what's happening as the disease progresses. In all patients I saw inflammation in their brains. The more inflammation they had, the worse their prognosis. My fellowship will continue my work investigating inflammation. I'm now studying biomarkers to see if we could use blood samples to show markers of inflammation. By creating more precise fluid biomarkers it will improve earlier screening and reduce the need for patients to have to wait to have a brain scan.

"We know in people living with PSP & CBD their brain immune system is malfunctioning and is over activated. While brain scans show a visual image of a specific brain change at a time, by using blood samples we can test for different things and targets. We want to develop a test that will tell us about which part of the immune system is involved in these conditions, and how. Then, we need to target the bit that's malfunctioning and find a way to switch it off. Crucially, this may not be the same approach in different patients. By developing more precise biomarkers, we will be able to better understand the patient's own immune system and what is the best approach for them. It will also enable us to better understand when is the optimum time for treatment.

"We have completed two major studies that show we can pick up inflammation in blood tests, that matches the level of inflammation in the brain. Publishing a scientific paper takes many months, so in the meantime we posted our results online so that it's available to researchers straight away. Communicating and sharing science advances is so vital, so studies can be replicated and carried forwards to help new treatments. We understand how urgent this work is, that's why it's so important we share our research as soon as possible.

"There's been a lot of excitement in the research community about our results. Research into inflammation in Parkinson's and dementia has usually used animal models or specialist brain scans. We show it is possible in humans with just a blood test.

"It's really important that people living with PSP & CBD are aware of research progress, and the invaluable part they play in it. They are the superheroes of research.

We simply couldn't do our work without guidance and assistance from people living with the conditions, and their families. Every day in our centre we see their dedication and determination to accelerate to research.

"People living with PSP & CBD are a vital part of the puzzle to solving this complicated problem. Their involvement in research strengthens and accelerates it. I'm optimistic we will get effective treatments. We've seen some recent breakthroughs in other neurological conditions and I believe this will happen for PSP & CBD too.

"Over the years I've seen increased public awareness of PSP & CBD. I know we still have some way to go, but certainly in the research community there is also growing awareness of these conditions and there are more clinical trials taking place than ever before. We are on the right path. We now have the ability to gain a great deal of information through brain scans and blood, and this will be a huge boost to clinical trials.

"Awareness is just as important as research. Through awareness we will be able to generate increased investment in research, and have laboratories focused on PSP & CBD, and have opportunities for people living with PSP & CBD to take part. Improved awareness also leads people to better care, and support from PSPA. I see in patients how important this is and that is why we always direct patients to the charity. It is there where they find a community and are able to access the support they need to live the best possible quality of life. This is equally important for the families and carers too. Together we form a community united against PSP & CBD."

## GET INVOLVED

Join our research network and get involved with research into PSP & CBD. Visit [www.pspassociation.org.uk/research/patient-carer-voices-in-research/register-your-interest-in-research/](http://www.pspassociation.org.uk/research/patient-carer-voices-in-research/register-your-interest-in-research/)



# "THE SYSTEM CAN'T KEEP UP WITH THE CONDITION"

Alison Roberts saw first-hand how little is known or understood about PSP as she navigated the NHS and social services with her Dad, first to try and get a diagnosis and then to try and get timely care.



While Alison's mum became the main carer for her dad, Alison helped coordinate the care he received from professionals. Alison shares their experience in the hope that it may help others.

"Dad was a very fit and active man. Even at 84, he'd go to the gym three times a week and did lots of volunteering. One day, just before lockdown, he couldn't get out of bed and his right arm was weak. We took him to the Emergency Department where he was diagnosed as having had a mini stroke. He was referred to the stroke clinic but the appointment was cancelled because we were in lockdown.

"Several months later he was seen by a neuro physiotherapist. By this point, Dad's walking wasn't right. He was still going to the gym but he wasn't steady on his feet. He was told he'd need walking sticks or a rollator. To Dad that was admitting defeat. He didn't want to go there. He was also aware that his speech was starting to slur and was becoming quite conscious of it.

"Dad was referred to a geriatrician who said Dad's symptoms might be down to a stroke or it could be something else. He sent Dad for CT and MRI scans. Dad's next referral was to a movement disorder consultant. The movement disorder consultant said

it wasn't Parkinson's. He thought it was possibly MSA but wasn't 100% certain. He referred Dad to another consultant. By the time of the next appointment Dad's PSP had progressed and he had to be wheeled into the room. Here, he was finally told it was PSP. Things went rapidly downhill.

"I did some research online about the condition. Lots of resources mentioned multidisciplinary care. In my ignorance I thought we would be given a point of contact who would coordinate Dad's care. It soon became clear this person was me!

"Dad's GP introduced me to the social prescriber at the surgery. This was really useful. He signposted us to people we should be contacting and told us to apply for attendance allowance to help cover the costs of carers. Following the meeting I got in contact with occupational therapy (OT) for an assessment. They had a three month wait but by this time Dad couldn't walk. In the end we took him to a mobility aid company to buy him some equipment and a wheelchair.

"My overriding experience of touring the NHS with Dad is that the system just isn't fast enough to keep up with the disease. Delays in getting a stairlift meant we ended up buying one. Delays in social services meant we ended up paying for carers. Delays in accessing equipment meant we ended up buying it.

"The best advice I received was from a couple of retired occupational therapists I met in a car park. While trying to find the correct change we struck up a conversation. They told me to get a book and write everything down. This was so helpful, especially when you're dealing with so many different health care professionals and various assessments.

"Dad felt abandoned by health professionals due to limited treatment options but he received great care from the local hospice. He sees the palliative care consultant every few months and feels supported by the staff.

"While Dad didn't have dementia, his personality was changing. He became obsessed with where his wallet was and would have mum going up and down the stairs to find it. You could see his frustration at not being able to do things himself. Mum lost so much weight. She was drained by the demands of caring for someone with PSP.

"Over time I was spending more and more time at their house. Dad saw the impact on Mum and how she was struggling. That really affected him. One day he suggested we looked into care homes. Dad picked out some he saw online. I looked at their CQC rating and then drew up a shortlist and went to visit them.

"The one we selected for Dad actually had prior experience of PSP. It's a lovely home and they take good care of him. I was so worried when he first moved in. It's taken quite a bit of adjustment for both him and Mum, but we're at a stage now when it feels normal.

"For me it was about retaining as much control over the situation as possible. I really didn't want us to get into crisis mode and then struggle to find a bed. I wanted Dad's move to a home to be planned and well managed.

"My experience with Dad has made me determined to help raise awareness. Apart from the consultant, no healthcare professional knew about PSP. We'd constantly have to explain his symptoms. I really want to become an education volunteer and help educate people on how complex and varied PSP is. I also want to highlight the lack of support that carers get."



## Alison's tips for finding a care home:

- Use websites including CQC, Age UK, Care Home Review to help shortlist possible homes
- Visit the homes in person and at different times of day
- Know what type or support and services you want for your loved one – the home we chose had beautiful grounds and a good sized room
- Know your budget in terms of local authority or funding support
- Ask your GP for a referral for a continuing healthcare funding assessment. Our district nurse assisted our application after it was initially rejected. It was accepted the second time around with her help.

## Benefits of the care home:

- Offers Mum respite and is local so we can visit as often as we like
- Caters to Dad's needs – such as providing soft foods which has reduced his choking incidents and chest infections
- Has a nursing floor which has plenty of staff to help with transfers
- Activities which keep Dad engaged.



# thank you TO ALL OUR SUPPORTERS



**£1,600**

### MEGAN'S MILES

Megan Hodgson, PSPA's Research Coordinator completed the Cambridge Half Marathon. Megan has so far raised over £1,600.



**£1,160**

### FOR MUM AND NANNA

Becky Slowe and her family ran the Cambridge Half Marathon, in memory of her mum and nanna Brenda. The family raised a wonderful £1,160.



### KYLE'S SKY HIGH

Kyle Wilson braved the heights and jumped out of a plane in a tandem skydive raising a wonderful £1,500.

**£1,500**



**£800**

### RUNNING FOR LINDA

Neil Callingham-Carter completed the Canterbury 10 Mile and the London Landmark Half Marathon in memory of his sister in law, Linda, who died from PSP (see page 16).



**£1,100**

### POWERED BY CAKE

Lindsay Nunn raised £280 with a bake sale to go towards her London Landmarks Half Marathon place. In total so far Lindsay has raised a brilliant £1,100.



### WALKING FOR OUR KEV

Sarah Cole, along with family and friends raised an incredible £1,800 walking in tribute to much loved husband, dad and grandad, 'Kev the Rev'.

**£1,800**



**£400**

### PHOEBE'S TREATS

Six year old Phoebe raised an incredible £130 with a bake sale to support mum Karen Linsey's fundraising. Karen will be running in the Brighton Marathon, and has raised over £400 so far for PSPA.



**£6,700**

### MEMORY MILES

Brothers Sam and Jonathan rowed the 23 kilometre distance from Whiftgift School to Twickenham Stadium, skied the 10.3 kilometre distance from Brentford Football Club to Chelsea Football Club, and biked the 168 kilometre distance from Bath Cricket Club to Lords Cricket Ground. All places that were important to the family. Even the dog got in on the action, and the family raised an amazing £6,700.



# GIFTS THAT GIVE

**PSPA 30 YEARS**  
CREATING A BETTER FUTURE FOR  
PEOPLE LIVING WITH PSP & CBD

For our 30th anniversary year, we have some unique limited edition items on sale. Celebrate 30 years of PSPA with us and support our vital work.

**POLO T-SHIRT**

£20



£7.50

**JUTE BAG**



**KEYRING  
TORCH**

£2.99



**PIN BADGE**

£2



£10

**TEDDY BEAR**



## ORDER ONLINE

To browse our products and place an order visit [www.pspassociation.org.uk/fundraising/shop](http://www.pspassociation.org.uk/fundraising/shop) or contact us on **01327 322414** or [fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk)