



# PSP/MATTERS

SUMMER 2021

## TIPS FOR STAYING ACTIVE WITH PSP & CBD

### ALSO INSIDE

- Read how our volunteers are raising awareness
- How you can get involved in the OxQuip Study
- Giving a new meaning to life after diagnosis

# YOUR SMALL REGULAR GIFT COULD MAKE A BIG DIFFERENCE TO PEOPLE LIVING WITH PSP & CBD

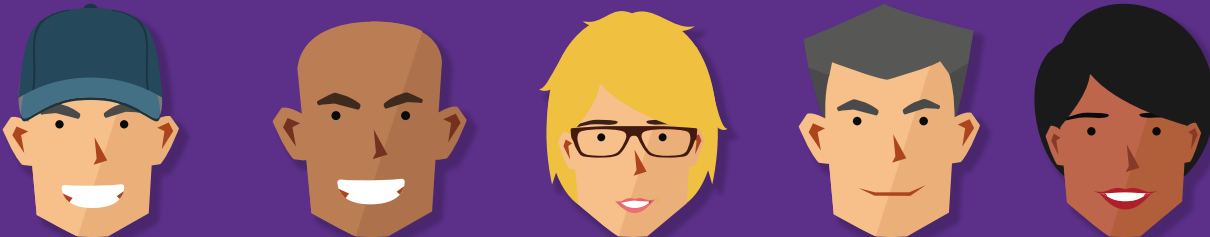
£5 per month could help us to raise awareness among local GPs



£10 to help provide information to support newly diagnosed families as they adapt to life with PSP or CBD and plan ahead



£25 per month could help progress important research



[pspassociation.org.uk/fundraising/donate/give-now-or-regularly/](https://pspassociation.org.uk/fundraising/donate/give-now-or-regularly/)



**WELCOME**  
Although we haven't seen as much sun this year as last, it definitely feels like there are brighter times ahead.  
  
Some of us will be welcoming back old friends, routines and family, whilst others might be embracing a new beginning of some sort, now things are beginning to open up again. As a new arrival here at PSPA, I can relate to that.

I joined the charity on 1 April as the new Chair of the Board of Trustees.

Over the past couple of months I have enjoyed getting to know the Trustees, staff and also some of our key supporters. And I look forward to working with everyone including you, our readers, over the next five years. As PSPA's flagship publication, I am delighted to welcome you to the summer edition of PSPA Matters.

As always there are a variety of personal experiences, from fundraising challenges to perspectives on giving new meaning to life following diagnosis (page 33).

We have information about the support we offer in terms of groups you can join for support, information and of course friendship and updates about our Helpline.

We also have research news from the team at the University of Cambridge, as well as details of how you can sign up to take part in the OxQuip Study from the comfort of your home (page 29).

You may remember the Research Priorities survey that PSPA circulated last year. In response to your answers you will find articles including tips for maintaining a level of physical activity (page 23) and how you can help support new research grants looking into living well with the conditions.

I hope you enjoy all the articles and don't forget you can check the PSPA website at any time for the latest updates on our work.

Thank you for your support

**Rowena Ironside**  
Chair of the Board of Trustees

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RUTH KIRKGOZE AND RACHEL WALKER



### CONGRATUALIONS TO OUR RAFFLE WINNERS

Thank you to everyone who bought and sold tickets for our 10,000 Voices raffle this March and April.

We are pleased to confirm the raffle has raised more than £20,000 to help fund our awareness raising efforts as well as our information and support service.

Congratulations to the 10,000 Voices Raffle Winners. The winning tickets are:

- **1st prize ticket number 009668** - Mrs Zita Foster
- **2nd prize ticket number 040554** - Mrs Illona Tredger
- **3rd prize ticket number 105535** - Ms Rachael Little

In addition, the luxury hamper has been awarded to raffle players who sold the most tickets. The hamper was sent to Rachel Walker and Ruth Kirkgoze in Kent, who together sold 600 raffle tickets to their friends, family, and work colleagues.

Rachel said: "John "Seeko" Seekings entered our lives in September 2020 with a diagnosis of PSP. Even when John's verbal communication declined he still managed to sing a song so clearly it brought tears to our eyes. He never lost his sense of humour and really loved a joke and a good laugh. The carers and activities coordinators built a strong bond with John as we spent many hours chatting, doing quizzes and games with him.

"When John's health declined I contacted PSPA and with his consent he was able to participate in monthly Local Group Zoom meetings. We gradually found out more about his illness which helped us to give him the best care and to improve his day to day living. "We asked to participate in the PSPA raffle and helped to raise much needed funds for this important cause. Following John's recent passing, which has left us all with a gaping hole, we will continue to support this wonderful charity in his memory."

Congratulations everyone and thank you for supporting PSPA.

### CARERS PODCAST LAUNCHED THIS JUNE

To help extend our support to people who are caring for a loved one living with PSP or CBD, we launched a new podcast on 10 June during Carers Week.

Each month, the podcast will cover a range of different topics related to caring for a loved one, with the first episode introducing the podcast and how it came into fruition.

You will be able to download the podcasts from the PSPA website and also via the Anchor app, just search for PSPA Podcast.

### PSP & CBD AWARENESS WEEK

We received a fantastic response to our PSP & CBD Awareness Week.

A range of awareness activities saw people get involved all week long. This included the launch of our new Red Flag resources, the recently updated GP Guide and an 'Ask the Helpline' session on Zoom.

In addition, we launched our very first 10,000 Voices Awards nomination period. The awards aim to help celebrate the lives and achievements of people living with PSP & CBD, their carers, healthcare professionals who support them, researchers, fundraisers and volunteers.

**To find out more about how you could nominate someone you know for a 10,000 Voices Award, visit the middle pages of this magazine where you can pull out a nomination form to complete and return to PSPA FREEPOST.**



### LOCAL GROUP SUPPORT IN NORTHERN IRELAND

During the pandemic, and thanks to Zoom, we have been able to offer Local Group meetings in Northern Ireland for the first time.

We have a small but dedicated group of attendees dialling into monthly meetings which take place at 6pm. Upcoming dates for meetings include 21 July.

If you live in Northern Ireland and would like to connect with other people living with PSP & CBD during the monthly meeting, please email [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

### CELEBRATE THE END OF THE LOCKDOWN WITH A PSPA TEA PARTY

Lockdown restrictions over the past year have meant we have been apart from our beloved friends and family for too long.

Celebrate the end of the lockdown whilst supporting our work, improving the lives of people living with PSP & CBD, by hosting a PSPA Tea Party this summer.

Whether it is held in your local park, back garden or with your family in your home, get together to enjoy a cup of tea accompanied by cake and conversation.

For more ideas to make your PSPA Tea Party celebration go well, you can request a tea party pack at [fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk) or download a pack at [www.pspassociation.org.uk/fundraising/check-out-our-new-tea-party-pack/](http://www.pspassociation.org.uk/fundraising/check-out-our-new-tea-party-pack/)



**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](http://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.







## PSPA SUPPORT NETWORKS

Our Local Groups have been providing essential support across the UK for many years, in fact we currently have more than 40 groups meeting regularly. More recently we’ve broadened our support by launching new group meetings to help keep you connected with people living similar experiences.

### YOUTH SUPPORT GROUP

With support from PSPA Volunteer Kathryn Embree, we launched the Youth Support Group in September 2020. This group brings together people aged between 18 and 30 years old, from across the world, who have a loved one who is living with PSP or CBD.

The group meets to support each other on a monthly basis at weekends. They also regularly check in using a private WhatsApp group and closed Facebook group.

The group are next meeting on 25 July at 7pm. Learn more about the group and complete the sign up form

at [www.pspassociation.org.uk/information-and-support/your-pspa-support-networks/pspa-youth-support-group/](http://www.pspassociation.org.uk/information-and-support/your-pspa-support-networks/pspa-youth-support-group/)

### NEWLY DIAGNOSED GROUP

Last year, we launched a Newly Diagnosed Group, aimed at those who have received a diagnosis in the last six months. We understand that our Local Group meetings, which bring together people at varying stages may be a bit daunting for people who have recently received their diagnosis so we decided to set up a group which allows those newly diagnosed to get together with others to share similar experiences. It also provides the opportunity to share and compare symptoms, ways



of managing them and ideas for future planning. Each meeting we welcome a guest speaker from the multidisciplinary team of health and social care professionals who support people living with PSP & CBD. The meetings are held as a block over six months.

The first meeting of the initial block of six took place in November and we welcomed over 30 people. The feedback has been extremely positive, so much so that many of those who attended want to continue to meet as a ‘not so’ newly diagnosed group.

The second block of six meetings began in May and again was well attended. The list to join the next block of six meetings beginning in November is now open to those people who have recently been diagnosed.

Find out more at [www.pspassociation.org.uk/information-and-support/your-pspa-support-networks/pspa-newly-diagnosed-group/](http://www.pspassociation.org.uk/information-and-support/your-pspa-support-networks/pspa-newly-diagnosed-group/)

### CBD GROUP

“Thank you so much for hosting the meeting this morning. I felt very emotional as it was the first time I had met other people with CBD. I am glad you’re going to do this meeting regularly, thank you. I think

we will all get comfort as well as information from the meetings.”

Earlier this year, we also launched a group specifically for people living with CBD. This group met for the first time on 10 March and helps to provide friendship, support and information to people living with CBD as well as their carers.

The group are next meeting via Zoom on 14 July at 11am.

Read more about the group and stay up to date with meeting dates at [www.pspassociation.org.uk/events-list/cbd-group/](http://www.pspassociation.org.uk/events-list/cbd-group/)

### ATTEND A MEETING

If you are interested in attending any of the above groups, please contact our Helpline to book onto the next meeting.

Email [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk) or call us on **0300 0110 122**.

**“I HAVE FOUND THE MEETINGS FOR NEWLY DIAGNOSED VERY HELPFUL. PSPA HAS BEEN A REAL HELP.”**





## RESEARCH SHOWS NEUROINFLAMMATION PREDICTS DISEASE PROGRESSION IN PSP

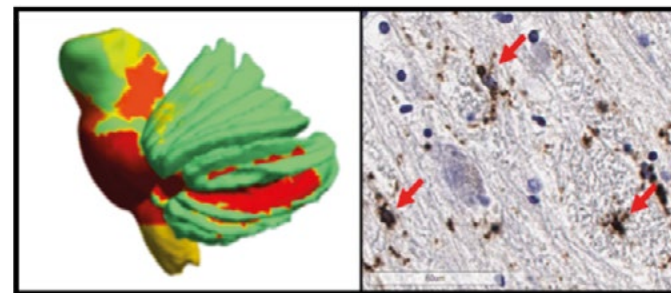
New research from the University of Cambridge, led by Professor James Rowe, has found neuroinflammation can predict how fast or how slow PSP symptoms progress in years ahead.

Considerable progress has been made in understanding changes associated with brain degeneration and the related symptoms. We now know harmful junk proteins like Tau which can accumulate in the brain cells, can lead to problems with, or changes in, memory, thinking, behaviour and movement. However, a lot is still unknown. For example, it is not clear why some people get worse faster than others.

Growing evidence suggests PSP is associated with Tau protein build-up but also with brain inflammation. Professor Rowe's research study aimed to look into brain inflammation in volunteers with PSP, using a special brain scanning technique called Positron Emission Tomography (PET) to measure both inflammation and the Tau protein levels. His team also used magnetic resonance brain scans (MRI) to detect any brain shrinkage. During the course of the study, James and his colleagues found that inflammation occurs in the same parts of the brain as the build-up of Tau protein, and these parts of the brain are most likely to shrink.

The important new discovery highlights the amount of inflammation at the start of the study helped to predict how fast or how slow individual participants would progress in the years ahead. The inflammation was more powerful to predict the progression of symptoms than either the Tau build up or brain shrinkage.

The study suggests measuring where and how much brain inflammation there is, could help to forecast the clinical progression of people with PSP, and help to target immune based treatments in those most likely to benefit. The study highlights that new treatment strategies could potentially target inflammation, to improve the outlook for people with PSP.



**Figure** – in the base of the brain, where there are lots of critical relay stations for movement and thinking, there is a build-up of inflammation as shown in red. This is due to the over-active microglia, the special immune system in the brain, shown under the microscope on the right.

You can read the full research paper, which has been published by the Journal of Neurology, Neurosurgery and Psychiatry at [www.jnnp.bmj.com/content/early/2021/03/17/jnnp-2020-325549](http://www.jnnp.bmj.com/content/early/2021/03/17/jnnp-2020-325549)



## STEPPING UP TO RAISE AWARENESS OF PSP DURING MARCH

This March, Olivia Roberts set herself the challenge of walking 10,000 steps a day to help raise awareness of PSP, after her grandad was diagnosed with the condition.

"My grandad was diagnosed with PSP four years ago and it has been horrible to see how the progressing symptoms have affected him, particularly during the pandemic.

Since PSP is so little known, I wanted to do something to help raise awareness of the condition so I decided to challenge myself to walk 10,000 steps each day for the whole of March. I chose to fundraise for PSPA through the challenge because I would do anything to help find a cure for PSP.

At the beginning of the challenge, it was me and my mum going out walking each day to ensure we reached the 10,000-step target. When restrictions eased, my dad and a neighbour joined us on our walks too.

The challenge really was a great way to do our daily exercise through the pandemic and I really enjoyed the company, with everyone who came and joined us on the walk, when they could. There were some days I struggled, as it is a lot of steps to get in each day for a month. But what kept us going was knowing we wanted to complete it for my grandad.

To help with the awareness raising, I posted every day about each of our walks on social media. We received so many nice comments, this also helped us to keep pushing forward with the challenge, come rain or shine.

On the last day of the challenge, we posted on various different social media and more and more people started donating to our Go Fund Me page. I was so happy we raised just over £600 for PSPA as I was only expecting to raise £100. I am so thankful people donated and that I've managed to raise awareness of this rare disease that not many people know about.

During the last walk, I felt so motivated to get my steps in. I couldn't wait to do that final post saying we have walked over 310,000+ steps in March. I really felt like I had achieved something especially through these difficult times. "

### GET INVOLVED IN 2021

If you would like to help raise funds and awareness this year, why not help show the Power of Ten?

Get together with your family or your friends to take on a ten themed challenge in support of our awareness campaign 10,000 Voices. Register your 10 themed challenge by emailing [fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk) or visit [www.pspassociation.org.uk/events-list/power-of-ten/](http://www.pspassociation.org.uk/events-list/power-of-ten/)

Read more about the 10,000 Voices campaign on page 16





## VOLUNTEERS MAKING AN IMPACT WITH ONLINE TRAINING SESSIONS

**Our Education Volunteers have been busy getting to grips with online platforms like Zoom, to ensure they continue to support and educate health professionals about PSP & CBD during the pandemic.**

After her mum passed away from PSP in 2011, and with keen presentation skills as a teacher, Janet Walch joined PSPA as an Education Volunteer in 2017, eager to make a difference.

"I've been an Education Volunteer for around four years now. I'm a teacher by profession, so I felt I had skills which PSPA could benefit from and the role was a great way to contribute to the charity's main aim of raising awareness.

I thoroughly enjoyed visiting different care/nursing homes and hospices in my area, to tell people more about PSP & CBD, so they are better able to care for any residents who may be living with the conditions.

When the pandemic hit, face to face training sessions came to an abrupt halt. Carol at PSPA had already received a request to help train some Parkinson's nurses about PSP & CBD in June. Since I was well versed in using online platforms for my job, I was more than happy to run a session for the nurses via Zoom.

It was the first online education session PSPA had run since the pandemic began, so I was a bit nervous about how it would all go. Luckily though, it all went to plan and the training was received really well.

At the beginning of 2021, Carol received a training request from a care home who had a resident living with a diagnosis of CBD. Although it was out of my



DENISE HUNT WITH HER DAUGHTER GEORGIE IRWIN AND HER MUM



JANET WALCH

area (I live in Manchester), Zoom made it possible for me to deliver the training to staff in the Croydon based care home easily.

I delivered the training across several weeks, running between 8 February and 3 March, for approximately 30 staff members in total, ranging from carers to nurses working at the home. Each session was 30 minutes long and covered information such as what CBD is, the cognitive changes that can occur and I also included the 'It's not Parkinson's' animation to finish with.

The staff members were really happy with the training and they felt it would help them to better understand how the resident with CBD was behaving. The training manager was also happy with how it went and was pleased with how clear the video stream was into the training suite at the care home. It is certainly something that I hope to be able to continue to do."

As well as running the Somerset Local Group, Denise Hunt is also passionate about raising awareness as an Education Volunteer, most recently presenting via Zoom to GPs in Bristol.

**"I SIGNED UP TO VOLUNTEER FOR PSPA FOLLOWING MY MUM'S DIAGNOSIS OF PSP IN 2018, AFTER SHE HAD BEEN EXPERIENCING ISSUES WITH HER VISION AND BALANCE FOR AROUND FOUR YEARS"**

DENISE HUNT

"I signed up to volunteer for PSPA following my mum's diagnosis of PSP in 2018, after she had been experiencing issues with her vision and balance for around four years.

"I was delighted to be given the opportunity to speak at a Bristol GP Continued Professional Development event on 25 February. I feel so passionately that earlier diagnosis can give families precious time together before the disease progresses, robbing them of being able to do the simplest of things such as going out for a coffee and catch up. It was very helpful for the GPs to hear about PSP & CBD from a clinical perspective but they were most interested to hear about the lived experience and how it impacts the entire family."

### PSP & CBD EDUCATION SESSIONS

If you are a healthcare professional who would like to arrange an education session for yourself and your colleagues, please contact Carol Amirghiasvand at [carol.amirghiasvand@pspassociation.org.uk](mailto:carol.amirghiasvand@pspassociation.org.uk)



# PSPA WELCOMES A NEW CHAIR TO THE BOARD OF TRUSTEES

On 1 April 2021, PSPA welcomed Rowena Ironside as the Chair of the Board of Trustees. With an extensive executive and non-executive career, Rowena will be bringing a wealth of experience with her to her new role.



ROWENA IRONSIDE

Rowena’s executive career was in the information technology industry, developing software and leading tech services teams in Europe, the US and Asia-Pacific. As such Rowena will bring a solid understanding of organisational development, financial oversight, risk management and diversity to the charity. She also has a wealth of non-executive experience, spanning the public, private and not-for-profit sectors in the UK, including five years as the inaugural Chair of the charity Compassion in Dying.

Currently, Rowena is a non-executive Director and past Chair of Women on Boards UK, an NED of the Digital Catapult and sits on the Steering

Committee of The Healthcare Improvement Studies Institute, Cambridge.

Rowena said: “I am delighted to be joining the Board of PSPA as Chair. PSPA plays a hugely important role in the lives of everyone touched by PSP & CBD, both in the UK and more broadly through its connections to international organisations. I look forward to the opportunity to work with everyone involved and contribute to the next stage of the charity’s development.”

**THE TRUSTEE BOARD**

Rowena has joined the four other members of the Board in overseeing PSPA’s senior management team to ensure the charity is run well and remains solvent. Trustees also ensure we comply with charity law and governance best practice.

The Board meets quarterly, giving all their time on a voluntary basis. The four other members of the Board are:

**PAUL INNESS**

“I’ve been a PSPA Trustee since September 2018 and recently took over as Chair of our Finance and Risk Committee, but my connection to PSPA stretches back a few more years.

“My mum, Sue Inness, lived with PSP until May 2019. Over the course of her journey, we used the Helpline, support materials and regularly visited the regional Local Groups, which I still do today, albeit on Zoom! We’re quite a big family and we were all affected in different ways by mum’s challenges and courage over the years.



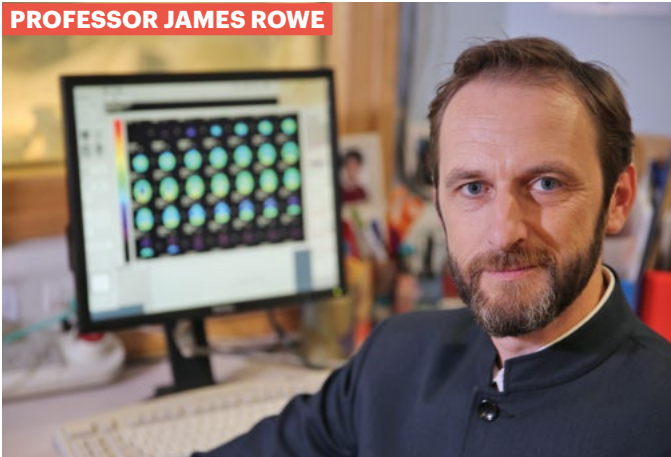
PAUL INNESS

“Like many people who have been affected by PSP or CBD, and who have leaned on the wonderful support and care of PSPA, you just want to put something back. To do whatever it takes to help raise awareness, funds, encourage our volunteers, and provide whatever guidance and skills the head office team can make use of.

“In my day job, I’m lucky to work with technology companies across the globe and start-ups from Oxford University. I guide them on making new technology products to help change our world. I’m hoping our PSPA funded researchers can find also a way to change the world for all those living with PSP & CBD.”

**PROFESSOR JAMES ROWE**

“As Professor of Cognitive Neurology, I study the mechanisms and potential treatments of PSP, Parkinson’s disease and frontotemporal dementia. I trained in medical sciences and experimental psychology at Cambridge, before clinical studies in Oxford and a PhD at the Institute of Neurology,



PROFESSOR JAMES ROWE

**“LIKE MANY PEOPLE WHO HAVE BEEN AFFECTED BY PSP OR CBD, AND WHO HAVE LEANED ON THE WONDERFUL SUPPORT AND CARE OF PSPA, YOU JUST WANT TO PUT SOMETHING BACK.”**

London. After further specialist training in Copenhagen, I returned to Cambridge in 2005, setting up the specialist NHS service for PSP & CBD, and where I now lead the clinical program within the Cambridge University Centre for Parkinson-plus.

“Away from Cambridge, I am Associate Director of Dementias Platform UK, leading the academic-industrial partnership for experimental medicine, and Chief Scientific Adviser to Alzheimer’s Research UK. My work brings together multiple types of brain scanning with genetics, drug studies and computer modelling of the brain, to understand PSP, CBD and related disorders; and more importantly to develop new treatments.

“It has been a great honour to serve as Trustee to PSPA over the last three years, and to be re-appointed to another term. PSPA punches above its weight in research, making every penny spent on research really count. The impact of PSPA’s research investment is felt across the UK and internationally, through major collaborations like PROSPECT, and in bringing international researchers together at symposia, online meetings and the co-founding of PROMOTUS.”

**JAMES NOBLE**

“I currently work as a social researcher with nearly 25 years’ experience working with the Government and charities on a range of social policy issues.

“I am currently working with charity think tank New Philanthropy Capital where I support lots of different charities to think about what they are





JAMES NOBLE

aiming to achieve and measure the difference they are making.

"I began volunteering with PSPA in 2016 because my mother-in-law was diagnosed with the disease and I later joined the Board in 2019. I have supported PSPA to think about its future strategy and helped run a survey of all PSPA members, which we are hoping to repeat this year."

#### JON GARRARD

"I first heard of PSP back in 2014 when my dad, also a great mate of mine, was diagnosed.

"Five minutes and a Google search later, my world had collapsed and I was left with lots of questions. Thankfully these questions were answered by calls to the Helpline, visits to the website, information packs, and by attending our Local Group, my first real benefit from PSPA - answers.

"As time went on and I saw the effects PSP was having, I hit a real low point and my wife, thankfully, reminded me that I'm an optimistic person and that I should turn a negative into a positive, so I channelled my emotions into fundraising for PSPA, this gave me a real focus and helped me feel like I was fighting back. Having a charity to get support from but also give support back to was a great source of motivation and inspiration for me.



JON GARRARD

"I've really enjoyed volunteering for PSPA as a Trustee. From hosting Family and Friends' days, pitching for pro bono branding, and working with the team on various design projects, most recently the spring edition of PSPA Matters.

"I was shocked when I found out how small the charity is in terms of staff numbers, we really are a small charity that punches well above our weight and I'm proud to play my part."

#### THANK YOU

This April, two PSPA Trustees, Barbara Johnston and Steve Le Hellidu, completed their four-year term on the Board.

Everyone at PSPA would like to thank Barbara and Steve for their dedication and support during their term and we wish them well for future endeavours.



## GETTING READY FOR THE VIRGIN LONDON MARATHON 2021 AND 2022

When the Virgin London Marathon was postponed in 2020, #TeamPSPA runners moved their places to the October 2021 or the April 2022 London events. Here Sara Whittaker tells us why she signed up and how she has stayed motivated, despite the delays.

My dad was diagnosed with PSP just a month after I completed the Blackpool Marathon in April 2019, only my second ever marathon. This news hit me hard and got me thinking about what I could do to raise awareness and funds for this illness, which I had no knowledge of prior to that date. My thoughts turned to the London Marathon and I unsuccessfully applied for a ballot place.

Whilst exploring PSP I came across PSPA and saw they had some charity places in the marathon, so I applied. I remember the day in September 2019 when I got a phone call from the charity, offering me a #TeamPSPA place in the London Marathon 2020. This happened to be the same day as my dad's consultant appointment, which for me was a clear sign it was meant to be.

Training for the marathon was going well, then in March 2020... lockdown happened. It was so hard to keep motivated during this time. I realise I'm not a lonely runner and prefer to run with friends. Training halted particularly with no goal of London 2020 to aim for. I decided to take part in the virtual London Marathon on 4 October, running the 26.2 miles locally supported by my running friends.

I was able to move my #TeamPSPA place from 2020 to April 2022. I opted for this date in order to avoid hot summer training runs, which I am not keen on. Unfortunately, a couple of days after completing the virtual London Marathon, I received a message from the COVID-19 track and trace app, telling me I had to self-isolate for 14 days. I don't have a large back garden and this impacted on my motivation for

running. Once released I couldn't find any motivation to run at all but fell in love with weight training and I took up walking, often doing between six and ten miles a day. The walking helped to bring back my passion for running in March. Although my first run of 2.5 miles felt like a run of 25 miles, it has got easier.

I'm back training again with my running club bubble of six friends, three times a week. Given I'm not running the marathon until April 2022, my focus now is to stay active and remaining injury free. I'll begin a full training plan from December onwards. I'm sure in the blink of an eye I'll be on the start line of the London Marathon albeit two years later than planned.

Whilst it's been a whole rollercoaster of emotions since that initial phone call confirming my place, one thing that keeps me humble and motivated is, the delays and frustrations, are nothing compared to what my dad faces each and every day living with PSP."

Keep up to date with Sara's training and support her at: [www.justgiving.com/fundraising/sara\[1\]whittaker2?utm\\_id=124](https://www.justgiving.com/fundraising/sara[1]whittaker2?utm_id=124)

#### Join TEAMPSPA

Places are now available to join Sara in #TeamPSPA for the London Marathon in April 2022. If you would like to take part in this iconic event, you can register to join our team for just £99 with a sponsorship target of £2,500.

Sign up by emailing [fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk)





Mohinder Dosanjh got involved in the 10,000 Voices campaign after her husband Paramjit was diagnosed with PSP last year. Here Mohinder shares her husband's diagnosis journey and how she has helped raise awareness.

"My husband Paramjit was poorly with ulcerative colitis so we thought symptoms such as eyelids closing and stiff muscles, were due to the weakness caused by the colitis.

During one of the appointments with a gastroenterologist in September 2018, the consultant voiced concerns that Paramjit may have Parkinson's from his facial expressions and the way he walks.

The consultant wrote to Paramjit's GP to get him referred to a neurologist, who then formally diagnosed Parkinson's.

We, as a family, then sought a second opinion privately in September 2020, where Paramjit was then diagnosed with PSP.

My husband's symptoms have progressed quite rapidly since then. He hardly speaks, has problems

swallowing tablets and fluids too. Since February 2021 he completely lost his mobility, is unable to support his weight and unable to stand or walk.

PSPA's Local Groups have been so helpful and supportive, when I saw the charity promoting the 10,000 Voices campaign I really wanted to get involved and give something back. Since there is no treatment for PSP & CBD and after seeing how much my husband has been struggling, I really want more people to know about this horrible disease, and how to spot it.

I decided to raise awareness by writing to my MP about it and I will be distributing Red Flag posters to GP surgeries close by. I regularly attend a community group and on 10 May, with support from PSPA's Volunteer Roger Bowley, I hosted a Zoom awareness talk. Everyone including my MP and GP found the talk interesting and afterwards they all donated to PSPA, raising almost £1,300."

## HELP US UNDERSTAND HOW PEOPLE CAN LIVE WELL WITH PSP & CBD



In recent years, research into PSP & CBD has advanced rapidly, helping us to better understand the causes and symptoms, and pointing the way to new treatment possibilities. However, there has been very little research into how people can continue to live well, feel well and remain independent with the conditions.

To aid research in this area, at the end of May, PSPA launched an appeal to raise £30,000 to fund research into how people can live well and independently for longer.

This research funding will be available to researchers or healthcare professionals looking into one of the top five priorities highlighted in our research survey last year. These were identified as:

- Balance
- Communication
- Dexterity
- Pain
- Multidisciplinary team approaches.

"To understand what works best and how we can help improve people's quality of life, we want to offer grants to fund research projects into living well with PSP & CBD. To make this possible in the next 12 months, we are calling for PSPA supporters to donate to help fund this vital research."

Bo Mandeville was one of the survey recipients who suggested living well with PSP & CBD would be a good priority for PSPA research. Bo said: "My main obstacle to living well is loss of independence. Retaining a sense of self-worth is also a direct result of being able to be independent in as many areas as possible, for as long as possible. For me it has been essential to maintain this illness does not define me. It's simply something I accept living with.

To have my family better understand how the illness affects me and how I find myself unable to do simple things is important too. For them to know I am not reluctant to join in but the symptoms make it too hard. Living with a progressive disorder means having to constantly adjust, mentally and practically, so understanding how I can live well at each stage is key."



Professor Nigel Leigh, Chair of PSPA's Research Committee, said "Last year, PSPA supporters shared in our research priorities survey, they want more support and information to enable them to live well and feel fulfilled at all stages of PSP & CBD.

### SUPPORT OUR RESEARCH APPEAL

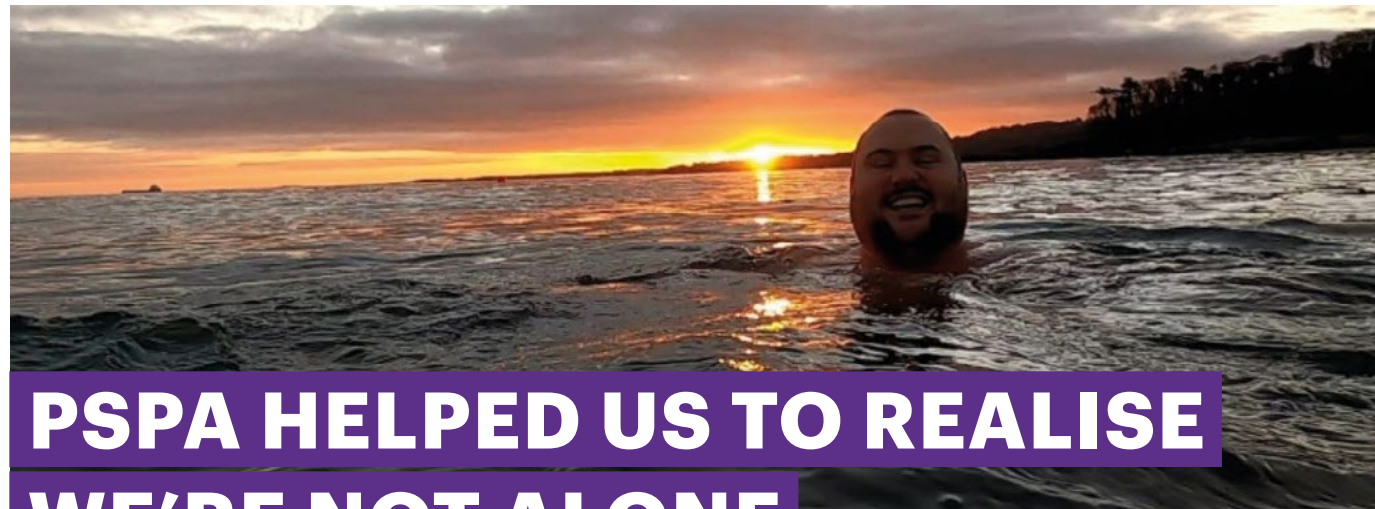
If you would like to help PSPA raise £30,000 to launch the Small Research Grant scheme, you can donate to the appeal in three ways:

**By telephone:** call us on 01327 356136

**On our website** visit:  
[www.pspassociation.org.uk](http://www.pspassociation.org.uk)

**By post:** Write a cheque to PSPA and post it to FREEPOST PSPA





## PSPA HELPED US TO REALISE WE'RE NOT ALONE

After Marc Watters' mum was diagnosed with CBD, he and his family felt quite alone as they faced the challenges the condition can bring. Then they linked in with PSPA and now both Marc and his mum are keen to raise as much awareness as possible.

"My mum was diagnosed with CBD five years ago, although she had been unwell for a few years before so we think symptoms actually began around 2014.

Initially, since the disease is so rare, health professionals had never come across her illness before. Mum didn't really tell anyone about her diagnosis as she has little information or knowledge of the disease which was a very frightening, lonely and challenging time for her. After linking in with PSPA via their Local Group meetings and realising so many people have the same experience, having never heard of CBD before their diagnosis, mum decided she wanted to start telling people. She wants to make people more aware of the condition and to also ensure others did not have the same early experience she had during her diagnosis.

I wanted to show mum as much support with this as possible and so I started thinking about taking on a challenge, not only to push myself but to also raise awareness of CBD and funds for PSPA too. I'd already completed a consecutive 30-day cold water sea swim, just to challenge myself, physically and mentally, so I knew I had the determination needed to complete an activity. I also knew there was plenty of support available from my friends and family, as I was surprised at how many people cheered me on whilst I swam and sent me messages of support. Some people even joined me in the water too.

This time though, I wanted to do something different. Wanting to loose a bit of weight I decided to focus on this as well as to tie in with PSPA's 10,000 Voices campaign by aiming to lose three stones in 90-days by walking at least 10,000 steps a day.

I feel really proud to take on this challenge, as I'll not only be fundraising to support a really helpful charity, but I'll also be assisting mum to spread the word about CBD too.

I started my challenge on 19 April, regularly posting my Fitbit step count on social media so people can see how I am doing. I also host a live social media weigh in for accountability. Two months in and I have lost 25lbs as well as raised £1,000 so far for PSPA which is amazing.

I'm so thankful to each and every person who has donated and supported me in my challenge. During the last month, I aim to increase my fundraising target to encourage people to keep sponsoring me, keep sharing information about CBD and keep supporting my mum."

You can read updates from Marc about his challenge and show him some support on his JustGiving page: [www.justgiving.com/fundraising/marc-watters](http://www.justgiving.com/fundraising/marc-watters)

## 10,000 VOICES AWARDS

### NOMINATION FORM

## PSPA 10,000 VOICES AWARDS

To celebrate the bravery, support and achievements of the PSP & CBD community, PSPA are launching the 10,000 Voices Awards.



The awards will recognise all people living within the PSP & CBD community, including people diagnosed with the conditions, carers, researchers, healthcare professionals, volunteers, fundraisers and campaigners.

Please help to shine a light on the people who you know from the PSP & CBD community, by nominating them for one of our awards.

THE TEN AWARD CATEGORIES ARE:

ALWAYS AMAZING AWARD FOR SOMEONE LIVING WITH PSP

The Always Amazing Award will be given to someone who has shown courage and determination whilst living with PSP. As a positive role model they may have shared their experience to provide inspiration and support as they help to improve the lives of people living with PSP & CBD.

ALWAYS AMAZING AWARD FOR SOMEONE LIVING WITH CBD

The Always Amazing Award will be given to someone who has shown courage and determination whilst living with CBD. As a positive role model they may have shared their experience to provide inspiration and support as they help to improve the lives of people living with PSP & CBD.

CARER OF THE YEAR AWARD

This award will be given to an unpaid carer, a family member or friend, who has been looking after someone they know who is living with PSP or CBD, helping them to live the best life they can.

VOLUNTEER OF THE YEAR AWARD

The Volunteer of the year Award will be given to an individual who has volunteered time to support other members of the PSP & CBD community. This could be by organising Local Group Meetings, helping out at PSPA events, educating health professionals or by providing companionship calls.

FUNDRAISER OF THE YEAR AWARD

This award is for a fundraiser who has shown creativity and determination in raising awareness and funds, big and small, for PSPA, despite the challenges of living with or caring for someone with PSP or CBD.

CAMPAIGNER OF THE YEAR AWARD

This award for a PSPA campaigner who has helped raise awareness of PSP & CBD to the general public and healthcare professionals so they are more aware of the conditions, how to spot them and how best to manage symptoms.

RESEARCHER OF THE YEAR AWARD

The Researcher of the year Award will be given to a researcher or health professional who has been studying PSP & CBD and has shown collaboration and innovation as they help to progress understanding of the conditions, how to spot the signs and how best to manage the symptoms.

HEALTHCARE PROFESSIONAL OF THE YEAR AWARD

This award will be given to an individual who has gone above and beyond in their efforts to support individuals and families living with PSP or CBD. This may include showing innovation whilst assisting PSPA developing or delivering services and information, improving care pathways or introducing best practice in their area.

CORPORATE OF THE YEAR AWARD

The Corporate of the year Award will be awarded to a company or organisation who has given outstanding support to PSPA by getting involved in fundraising, campaigning and volunteering initiatives.

THE 2021 IN MEMORY AWARD

This award will be given in memory of the courage and achievements of a family’s loved one. The person being honoured will have lived with PSP or CBD themselves, and through their determination to live life to the fullest, have created legacy within the PSP & CBD community.



NOMINATION FORM

Nominee details

Name

Age

Address

Telephone number

Email address

What Award are you nominating your nominee for?

What is their connection to the PSP & CBD community?

In no more than 500 words, please tell us why you think your nominee deserves the award. Please pay close attention to the award criteria and try and match any achievements to PSPA’s values: Positive, Collaborative, Innovative and Supportive (continue on a separate sheet of paper).

Please provide any photos, articles or evidence that may support your nomination.

Is the nominee aware that you have made this nomination? Yes / No

Nominators details

Name

Address

Telephone number

Email address

Will you be happy to take part in any promotion of the awards, either on social media, the PSPA website, in PSPA Matters or in the media? Yes / No

Please send this completed form to **FREEPOST PSPA** by Sunday 25 July.

PSPA will use your personal information only for the purposes for which you have given us consent. We will keep your data confidential and safe, and will never swap or sell it and you can always withdraw your consent at any time by emailing **info@pspassociation.org.uk** or calling **01327 322410**. You can see our privacy statement at **www.pspassociation.org.uk/home/privacy-policy** which explains how we collect, store, manage and use your personal information.



# PRIORITISING NEUROLOGICAL CONDITIONS ACROSS THE UK

In recent years, collaboration has really helped to strengthen our voice and raise awareness of PSP & CBD. Our work with the Neurological Alliance in Scotland and CHC Alliance are good examples of how we aim to keep PSP & CBD priorities in healthcare.

Ahead of this year’s Scottish Parliament elections, the Neurological Alliance of Scotland organised a Hustings event offering member organisations the opportunity to quiz political parties on what steps they will take to put neurological issues at the forefront of their work over the next term.

The 90 minutes Hustings meeting was brilliantly refereed by Tanith Muller, the Chair of the Neurological Alliance of Scotland who also is Policy and Campaigns Manager at Parkinson’s UK Scotland.

PSPA Scotland Manager, Gill Dickson, who attended the event said: “The Hustings was a great example of communicating the policies of all the main parties to a live audience. Each candidate had prepared for the session either by sharing their previous knowledge or experience of neurology issues or by reading the National Framework: - Neurological care and support: framework for action 2020-2025. The audience was a mix of Neurological Alliance of Scotland member organisation representatives and people living with the conditions. People could add additional comments and questions in the online chat function meaning that there was real-time interaction with candidates and what was being said. It was particularly interesting to hear of the experiences of some people who live rurally, for example for patients on the Scottish islands a consultant visit, on the mainland can be a three-day trip! Working collaboratively with member organisations in the Neurological Alliance of Scotland is fantastic and produced an excellent event giving us direct access to the election candidates. As new members return to the Scottish Parliament, PSPA will continue to ensure we have a voice in this Alliance whilst also taking every opportunity to communicate the specific needs of people with PSP & CBD.”

PSPA are also pleased to be one of 18 charities who belong to the Continuing Healthcare Alliance.

PSPA Helpline Team Leader, Jules Brown attended a recent meeting, where discussions surrounded the implementation of Continuing Healthcare (CHC) and checklist, with Clinical Commissioning Group involvement. Talks were also held about how the Alliance can influence and support NHS England to ensure the framework for CHC is adhered to and the funding is accessible to all those eligible to receive it.

Jules also attended a NHS Continuing Healthcare and NHS Funded Nursing Care Stakeholder meeting in May, which are held every quarter. Attendees include Trish O’Gorman, Head of NHS CHC for NHS England, and the NHS CHC Regional leads, alongside representatives from the Department of Health and Social Care and charities across England. At this meeting, discussions centred on implementation of CHC during the pandemic. After being put on hold, assessments were reintroduced from September 2020 and Trish confirmed the backlog of almost 38,000 deferred assessments, have now been cleared. The implementation of digital assessments during the pandemic was overall welcomed, however there was caution from CHC Alliance members that face-to-face assessments were still necessary in many cases.

Jules said: “The CHC stakeholder meeting is an excellent opportunity to share issues reported to us on the Helpline by people living with and caring for people with PSP & CBD. NHS England are keen to hear about the experiences of people who are applying for and receiving CHC. There was recognition of the difficulties people have experienced in not being able to see their loved ones in care homes and the impact this has had on their ability to discuss increasing or ongoing care needs with staff. It was a positive experience with open encouragement to raise problems and best practice at future meetings”



## ‘USE IT OR LOSE IT’ PHYSICAL ACTIVITY FOR PEOPLE LIVING WITH PSP & CBD

People living with PSP or CBD can experience difficulties which may weaken or disable them meaning they may need help with everyday tasks. Rakesh Kumar, Senior Physiotherapist at Ysbyty Gwynned Hospital in Bangor, shares how staying active can help improve strength and what types of exercise to focus on.

“Researchers have discovered a robust link between physical exercises and the improvement or delay of some neurodegenerative symptoms, which include a breakdown of motor skills. In fact, people living with neurological conditions, such as PSP & CBD, who exercise, experience less stiffness, also a reduction in, and possible reversal of muscle wasting. Research also has shown that exercise can improve gait, balance, tremor, flexibility, grip strength, and motor coordination. Some specific benefits of physical activity may include, increased lean muscle and bone density, stronger and more supple joints, and improved range of joint motion. Current evidence shows significant positive effects in favour of exercise

on pain, function, and quality of life outcomes within the short and long-term.

My advice for people living with PSP or CBD who want to continue to stay active, is to:

- Always warm up before beginning your exercise routine
- If you want to exercise for half an hour, but are new to exercise, start with 10-minute sessions and build up to 30 minutes
- Exercise your facial muscles, jaw, and voice, when possible, to improve throat strength. Including singing or reading aloud, exaggerating your lip movements, or making faces in the mirror



- Try chewing food vigorously, avoid swallowing large pieces. Instead, chew each piece for a minimum of 20 seconds
- Try water exercise, like aqua aerobics, which is easier on the joints and needs less balance
- Always exercise in a secure environment. Avoid slippery floors, poor lighting, throw rugs, and other potential dangers
- If you have difficulty balancing, exercise within easy reach of a grab rail, or use the back of a chair to steady yourself
- If you have trouble standing or getting up, exercise in a chair or in bed instead of on the ground
- Select a hobby or activity you enjoy and can keep doing. This might include gardening, walking, swimming, water aerobics, Yoga, Tai Chi
- Rest your muscles between strength training sessions, three sessions of strength training a week is sufficient
- Activities should be performed at a moderate intensity, which is typically a five or six on a scale of 10 and causes your pulse to quicken. As a rule, if you are doing moderate-intensity activity you will be able to talk, but not sing a song, during the activity
- Combined upper and lower body exercises. If you go to the gym the elliptical / cross trainer is worth a try
- Lift and lower a hand weight (light dumbbell), bottle of water or tin of beans. Attempt to do 10 to 15 repetitions of every exercise. This counts as one set. Gradually work up to doing two sets of 10 to 15 repetitions of every exercise. You can increase the weight over time if you wish. Make certain to rest for one or two minutes between each set of exercise.
- Stop if you are experiencing unusual symptoms or pain



PEOPLE WHO HAVE CONTRACTURES

In many neurological conditions contractures may be a complication, including PSP & CBD. Contractures are a tightening of muscles, tendons, ligaments, or skin. It makes it hard or impossible to move nearby joints. Problems that affect nerves and muscles can lead to contractures as can a change in muscle tone, otherwise known by the medical term ‘spasticity’ which may be a symptom of PSP & CBD. Contractures may result in deformities, pain, and skin breakdown and can restrict activity and participation in both exercise and other aspects of daily living. Therefore, the goal of treatment is to ease pain and increase function of the limb.

Movement, exercise, and physical therapy may prevent this problem. Stretching is widely used to treat and stop contractures. Stretching may be self-administered on the advice of a physiotherapist, applied manually by therapists, or administered with positioning programs or by splinting. The duration of stretch varies by on how it is applied. For instance, stretch administered manually is applied for a couple of minutes each day, whereas stretch administered through serial casts is applied continuously for days or weeks at a time. If contractures are a problem for you, please seek advice from your physiotherapist or neurologist as other treatments may be available.

DEEP BREATHING AND RELAXATION

When we are tense or feel anxious, we inhale shallowly and quickly. At rest, we inhale more deeply and completely. By utilising stomach breathing, we can invigorate the unwinding reaction of our bodies, helping us to relax. Furthermore, taking care of our breath assists us with our mental and physical wellbeing. In neurological conditions like PSP & CBD



the breathing pattern, can become worse over the time because of the poor breathing muscles. The accompanying exercises can help you to improve your breathing. Only three minutes of breathing practice will aid relaxation. Practice for three to five minutes consistently every day, doing this at the same time each day will help to make it part of your everyday routine.

STOMACH BREATHING EXERCISE

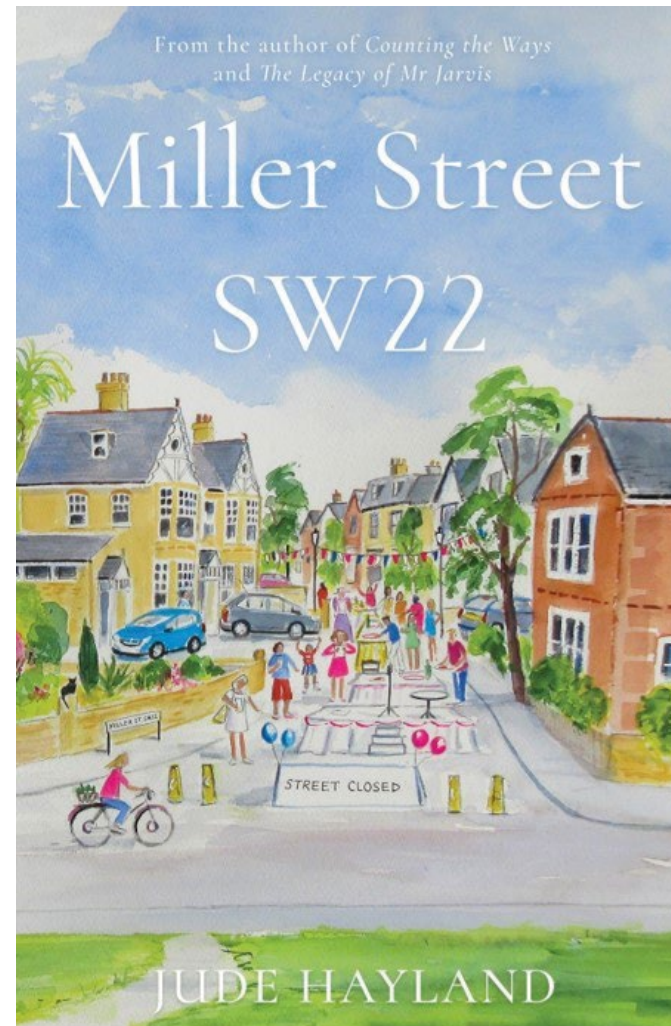
1. Place one hand on your midsection directly underneath your ribs, note the degree of pressure you are feeling.
2. Breathe in gradually, taking a deep breath through your nose into the “base” of your lungs. In case you are breathing from your mid-region, your hand ought to really rise. Your chest should move just somewhat while your abdomen grows (In stomach breathing, the diaphragm – the muscle that isolates the lung depression from the abdominal cavity – moves descending. In this manner, it causes the muscles surrounding the stomach cavity to push outward).

3. At the point when you have taken in a full breath, momentarily pause, breathe out gradually through your nose or mouth. Make sure to breathe out completely. As you breathe out, allow your entire body to simply give in and relax.
4. Do ten slow, full abdominal breaths. Attempt to keep your breathing smooth, without swallowing in a major breath or allowing yourself to breathe out at the same time. It will help to slow down your breathing if you slowly count to four on the inhale, and then slowly count down from ten down to one during the exhale. one number with every exhalation. On the off chance that you begin to feel discombobulated while rehearsing stomach breathing, stop for 15 to 20 seconds, at that point start once more.
5. Expand this exercise if you wish by doing two or three sets of abdominal breath remembering to count backwards from ten to one for each set. Five entire minutes of stomach breathing will have a positive impact in lessening tension



# A NOVEL IDEA FOR PSP

Following the death of her mother Mavis, writer Jude Hayland was keen to share her experience of how PSP impacts the whole family and in her new book *Miller Street SW22*, she does just that.



“The neurologist looks at the three of us. Me, my sister and sitting quietly between us, our mother, Mavis, already a shadow of her former vibrant self. “It’s something called Progressive Supranuclear Palsy,” he says then adds, seeing us exchanging looks, “but I suspect you’ve diagnosed that before me.” And he was right. But it was entirely by chance.

One afternoon in 2006, I happened to catch part of a Radio 4 health programme that was talking about a neurological illness with symptoms remarkably similar to those we were seeing in our mother. Symptoms that her GP and even a geriatrician had put down to ‘the natural aging process’ when we had expressed our concerns.

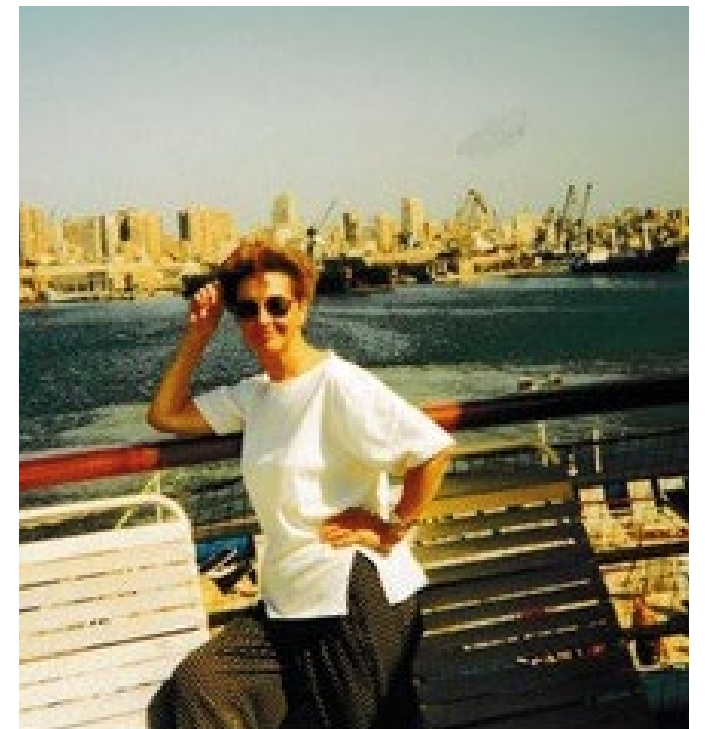
Our mother was a woman who had always looked and behaved considerably younger than her years. Attractive, glamorous, passionate about the theatre, exuberant and excellent company, she had been a drama teacher, training as a mature student, and had not retired until she was 72. Moving down to Winchester to be close to me and my sister and our

families, our parents, sociable, outgoing people, had looked forward to the next part of their lives.

But within a couple of years, Mavis began to change. Small, insignificant signs at first that meant little until viewed in retrospect. She started to be uncharacteristically irritable, short-tempered, her conversations lacked coherence and chronology and she increasingly began to withdraw from conversations if she could.

Our mother, always holding the limelight, always with a view or opinion to share, was becoming inhibited. But the GP, the geriatrician, were dismissive. Even ageist.

When Mavis began to dislike her own company, growing anxious when our father was out for a few hours, we knew something was seriously wrong. Our parents had always been very independent people. They both had their own interests that they had pursued throughout their long marriage and had never been the type of couple perpetually in each



## “MY NEW NOVEL, MILLER STREET SW22, FEATURES A CHARACTER, LYDIA GOUGH, WHO HAS A DEGENERATIVE NEUROLOGICAL CONDITION.”

other’s company. Now, suddenly, our mother was utterly lost without him, fretting like a frightened child when he was absent.

The day I saw how her handwriting had declined was another of those signals of alarm. Writing me a cheque for my birthday present, I could hardly decipher the words. Her signature had become a freewheeling scrawl. And she began to fall. Sudden tumbles caused by no apparent obstacles so that we became concerned that she was unsafe on the stairs, out in the street. We went back to the GP.

“I expect she’s had a mini stroke or two,” was the diagnosis, “TIAs. It’s quite common. She’ll get over it and be fine again in a week or so.”

But Mavis wasn’t ‘over it’ in a week or so. In fact, the only change in her was a marked decline over the coming months. Her speech, always crisp and clear, became mildly slurred as if suffering the effects of too much alcohol. And the volume of her voice was subdued so that it was often hard to hear her. Her

walking was slow, her balance unreliable, and we resorted to a wheelchair in order to take her out. Then that Radio 4 medical programme followed by a couple of hours researching on the internet.

We were back at the GP surgery, prepared to be insistent.

But the doctor, noting the considerable worsening of Mavis’ condition, this time needed no persuasion. An MRI scan was arranged, followed by another visit to the geriatrician who sent us directly to the neurologist. Suddenly, our profound concerns were being taken seriously.

So back to the three of us in the neurologist’s small surgery, uttering my somewhat self-conscious explanation of the source of our ‘diagnosis’ and seeing him smile sympathetically.

“We should always listen to the families,” he says, “they are the ones who can tell very early on when something is wrong.”





At last we knew. We finally had the diagnosis of PSP after years of bewilderment and frustration. And even though we were all too aware of the prognosis, at least we had a context in which to understand.

Mavis had lost her health, her autonomy, her independence to this illness. But we too, as a loving, close family, were experiencing a loss – a kind of premature mourning for the woman who had been an incomparable mother, a spirited, capable and attractive wife. We all had adjustments to make.

Mavis was to live for another four years and four months, most of that time spent as a resident in a wonderful care home very close by who did their best to tend with dignity to her ever increasing needs. Our father, five years older, visited daily. Ironically enough, she outlived him by a year.

My new novel, Miller Street SW22, features a character, Lydia Gough, who has a degenerative neurological condition. PSP is not named, but it is clear from anyone who is familiar with the illness that Lydia's symptoms and decline, together with the difficulties of diagnosis, mirror PSP.

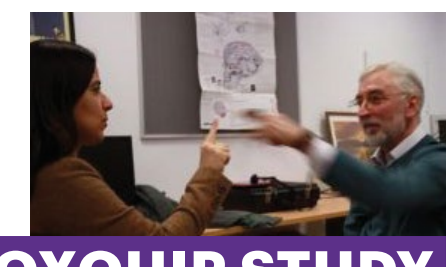
But this is a novel not a medical textbook. The focus is therefore not only on Lydia, but on her husband, Sam and their daughter, Polly, for the impact on

the immediate, loving family is something I could write about with honesty and potent memory. The emotions provoked by seeing a beloved parent, husband, wife or relation living with the symptoms of PSP are complex. It is why I wanted to write about characters in such a situation, about Sam and Polly Gough, to explore their sometimes perverse feelings as they grapple with the realities of Lydia's illness and prognosis.

I am sure our beloved mother, Mavis, would have approved."

Further details of Miller Street SW22 can be found on Jude's website: [www.judehayland.co.uk](http://www.judehayland.co.uk). Available from all online and high street booksellers including [www.pgwell.co.uk](http://www.pgwell.co.uk).

Jude will kindly donate 20% of the sales of her book to PSPA. To help Jude keep track of the sales, please email Jude to confirm your purchase at [judehayland@hotmail.com](mailto:judehayland@hotmail.com)



## NEW FUNDING HELPS EXTEND OXQUIP STUDY

Work on the Oxford Quantification in Parkinsonism study - OxQUIP, led by Professor Chrystalina Antoniades at John Radcliffe Hospital, Oxford, began in 2019 to help aid early diagnosis PSP. Here Professor Antoniades tell us more about the study and how people can get involved.

"It is estimated there are seven to ten million people with Parkinson's and PSP disease worldwide. Currently available treatments are symptomatic only, and while they may be very effective for a number of years, they do not have any preventive or disease slowing effect.

Potential new treatments are in the early stages of development and we wish to develop new ways of measuring Parkinson's and PSP symptoms as precisely as possible so when new drugs are ready to test, we are able to very accurately measure their effectiveness in clinical trials.

In the OxQuip study, we follow participants intensively over a two-year period, with the aim of identifying measures that can detect disease progression over much shorter time periods than is possible at present.

Within the study participants perform a range of simple tasks while wearing sensors that accurately quantify their performance. Measurements recorded included eye movements with infra-red cameras and body movements using accelerometers. Participants also perform cognitive tasks on a tablet computer, testing for example their ability to deduce the rules governing the movement of shapes on the screen.

Early data suggests wearable technology, combined with artificial intelligence and machine learning,

could offer the potential to accurately distinguish symptoms of Parkinson's from PSP.

To maximise the benefit from any potentially disease-modifying treatment for PSP an early and accurate diagnosis will be required so treatment may be initiated as early as possible in the course of the disease.

Thanks to new funding, we have been able to extend the study by two years, aiming to increase the number of PSP patients as well as extend the acquisition of quantitative data to the real-world setting of the patient's home. It is anticipated that this research will lead to publications aimed to support the movement disorder community in improving the diagnosis and management of people living with this debilitating condition."

### SIGN UP TO TAKE PART IN OXQUIP

If you are living with a diagnosis of PSP and can take part in video calls at home with Professor Antoniades' team, once every three months over two years, please email [chrystalina.antoniades@ndcn.ox.ac.uk](mailto:chrystalina.antoniades@ndcn.ox.ac.uk)





## “FUNDRAISING WAS A GREAT WAY TO SUPPORT MUM WHILST THE PANDEMIC KEPT US APART.”

Lucy Heady and her ten-year old daughter Rosa, were busy during Lockdown 2.0 making jewellery to sell in support of PSPA. Here Lucy and Rosa share why they wanted to fundraise for PSPA and what they did next.

“My mum, Rosa’s Nan, was diagnosed with PSP in July last year, however she had been unwell for several years prior to that. The way mum walked changed and her coordination was affected so eating meals was a bit difficult too. Over time, mum’s mobility has really declined and she’s now using a wheelchair.

My dad is mum’s main carer. We don’t live close by so helping out in a practical manner has been impossible during the lockdowns and restrictions.

Since we couldn’t be there to help mum and dad in person, me and Rosa were really keen to show our support in another way. Like so many other families, none of us had heard of PSP before so we thought we could do something that would not only raise some much-needed funds for PSPA, but would help raise awareness of the condition too.

It was Rosa’s idea to make earrings to sell for PSPA and in support of her Nan.

Once Rosa had made up a few pairs of earrings in different colours to give people an idea of what the earrings would look like. I took some photos and since I am quite active on Facebook, I posted the photos to my profile, telling my friends and family what we were doing.

Messages from friends and family soon came flooding in. People were sharing my post onto their profiles and so we quickly sold out of the first batch of earrings we had made. Rosa’s cricket coach bought a couple of pairs for this family. A pair of earrings even made it as far as America, with a friend buying some to send to friends in Virginia.



Although we suggested just £3 for a pair of earrings, most people were rounding up their donation to £5 or £10, and we received some donations from people who didn’t buy any earrings at all.

It felt really good to be contributing in some way. We did a really big push before Mother’s Day and in total we raised £639.

When I told my mum and dad about what Rosa was doing, they were really proud of her.

After Mother’s Day, we read about the 10k for PSPA virtual event in a newsletter and thought that would be a great way to continue our fundraising, whilst also tying in with our love of walking too.

Awareness raising is so important for such a rare condition, so in order to make people stop us and ask questions, we walked our 10km on 15 May wearing bright purple and orange wigs, to keep in with the PSPA brand.

It would have been great to have had more people involved in the walk, but we were limited this year due to the restrictions, so we will save that for next year.

Rosa added “I was feeling quite bored during the lockdown and because I wanted to do something for my Nan, I thought making jewellery and selling the items to help raise money for charity would be a great idea.

We ordered everything we needed online, such as charms, equipment and the packaging, and after making up a few pairs mum posted some photos onto her Facebook page. That evening was our



busiest day. So many people were donating and requesting earrings for themselves and friends.

We set up a little production line to keep up with the demand. I would make the earrings and attach them to the backing card. Mum would then place them into a little plastic envelope, add a sticker and wrapped them in tissue paper ready for posting. And then dad took them to the post office when he walked the dog each day. Any of the earrings we had to post far, we sent out in little pink bubble wrapped envelopes.

We sold out quickly and had to order more bits online so we could keep up with the requests. We got a few requests from other people living with PSP when PSPA shared our post onto their own Facebook page, which was great.

Mum got sent lots of selfies with people wearing the earrings, which reassured me that they really did like them.

I really enjoyed making the earrings and raising money for PSPA. We do still have some of the charms left so we might make more later in the year. Next though, we walked 10km locally in May. I wore a bright purple wig on the day and my brothers wore orange and pink wigs to help us stand out and raise awareness whilst we were completing the walk.”

Take a look at photos from Lucy and Rosa’s walk at [www.justgiving.com/fundraising/lucy-heady3](http://www.justgiving.com/fundraising/lucy-heady3)



# WHAT WE ACHIEVED IN 2020/2021

Every day, PSPA supporters do amazing things to help us continue our vital work in the PSP & CBD community...and beyond.

The past 12 months have been a challenge for everyone. Despite this, our amazing supporters and volunteers have stepped up to donate, run, walk, cycle, bake and swim to raise funds for PSPA so we can continue to develop and deliver information and support, raise awareness and fund research.

Thanks to these funds, you have helped us launch new information and support services. These include

the PSPA Support Grants, Newly Diagnosed, Youth and CBD Groups, funding for SpeakUnique voice banking services and a PSPA Podcast for carers. Thank you for everything you do for PSPA and the difference you help us make in the lives of everyone affected by PSP & CBD.

Here is just a few of the things you've helped us to achieve in the past year:

We've supported

**5400**

people living with **PSP & CBD**, carers and family members

We've responded to

**4800**

Helpline calls and emails

We've awarded

**23 PSPA**

Support Grants amounting to **£4800** and have responded to **240** enquiries and follow ups

We've provided funding for **six people** to bank their voice with **SpeakUnique** amounting to

**£1500**

and answered **64 enquiries**

We held

**192**

Local Group meetings via Zoom

We supported

**60** people living with PSP & CBD along with **45** carers at our monthly Newly Diagnosed Group meetings

We also brought together

**56**

people and their carers at our new **CBD Group meetings**

We host

**7,460**

members on **HealthUnlocked**

Engage with more than

**14,500**

followers on social media

1020

new people have joined the **PSPA community** in the last year

We now have

**191**

volunteers thanks to people coming forward in the past year

We've sent publications to help support

**102**

healthcare professionals

Provide information to

**43,707**

web visitors

Share personal experiences with

**10,648**

PSPA Matters subscribers



## GIVING A NEW MEANING TO LIFE AFTER DIAGNOSIS

When Julia Tickridge's husband Laurie Day was first diagnosed with PSP overlapping with CBD in December 2018, the couple were determined to find ways to give a new meaning to their lives. Julia shares their diagnosis journey, as well as how they've built a great support network and found new interests.

"The first real signs something wasn't quite right, were becoming apparent in 2015. Normally extremely articulate and clear in his communication, Laurie seemed to be unnecessarily repeating himself, focussing on a particular word or phrase, which was becoming obvious not just to me but other people. His speech was becoming both garbled and hesitant and he was starting to stutter and slur. His distinctive and beautiful handwriting was becoming smaller and illegible. He was also becoming increasingly clumsy. At first, I thought these signs were the after effects of major spinal surgery the previous year but they were lasting far longer than would have been expected.

My husband waited two years until 2017, before deciding himself, he needed to get his symptoms checked out because he realised all was not quite as it should be.

Initially our GP carried out a standard memory test and my husband's score was of sufficient concern for him to be referred to the local memory clinic for further investigation by a psychiatrist. At this stage it was thought Laurie was showing signs of vascular dementia.

We waited six months for an appointment (by this time mid 2018) and my husband underwent an MRI scan and a memory test again. His condition was described as a mild cognitive impairment and we left with no further signposting to sources of information or support. We were just asked to arrange an appointment for six months' time.

I set about researching this further which resulted in responding to a call, quite by chance, for people experiencing signs of early onset cognitive



impairment and their carers to take part in a research programme at UCL. We both thoroughly enjoyed participating and as a result inquired whether we could have a second opinion at the National Hospital for Neurology and Neurosurgery in London as I was concerned my husband was not showing classic signs of a dementia but potentially something rarer affecting younger people – possibly a frontotemporal dementia.

Our GP referred my husband for a second opinion and between September and December 2018, Laurie underwent numerous consultations and investigatory work which culminated in an initial diagnosis of overlapping PSP & CBD in December 2018. The diagnosis has since been updated to evolving PSP in October 2020.

Although challenging, Laurie's diagnosis has enabled us to face the reality of his condition and organise the multidisciplinary health and social care support we need now and when planning for the future. I need to stress, however, that communication between the various teams in different hospitals and other healthcare settings does not fully join up, meaning that we constantly find ourselves re-telling Laurie's medical history. Being as informed as he is does mean Laurie has been able to make decisions about his continuing healthcare and, although no-one can say what will happen in the future, we hope our proactive approach will help us avoid unnecessary emergency situations and so reduce our anxiety. This means that we can enjoy life to the full now.

The diagnosis has also opened up access to disability benefits such as Personal Independence Payment (PIP) which, in turn, can then unlock other sources of healthcare and financial support such as discounts on council tax and a Blue Badge for parking. Our local carers centre has also advised on getting on the access list of various cultural centres which enables a free carers ticket, and I am registered with the Carers Emergency card scheme should anything happen to me and my husband need care in my absence.

PSPA has been a tremendous support. We contacted our Local Group in Liverpool and were invited to join the meetings which, before the pandemic, took place every two months. Initially we were a little reticent because we knew that we would be meeting people living with PSP & CBD at different stages in their condition. But after a few months we joined in and are so glad we did as it enabled us to take more

control and meet others in a similar situation, the importance of which cannot be underestimated. We contacted the Helpline and received various leaflets (some of which I have shared with our GP) as well as an alert card which my husband carries to explain his condition in simple terms to other people when this is necessary. Our local speech and language therapy service also provided a laminated card to explain very simply the communication problems my husband is experiencing and to request patience and understanding from people he comes into contact with.

And thanks to PSPA funding, we are in the process of organising voice banking with SpeakUnique. PSPA has also awarded my husband a Support Grant to purchase a set of headphones with a microphone attached, to help with recording his voice. On top of this, the charity is liaising with our local speech and language therapist to enable us to get the best out of the voice banking service.

In addition, my husband signed up to take part in the PROSPECT study to play his part in helping scientists understand more about PSP and related conditions. We've also participated in eye tracking studies at UCL, the Tau-Tangles which uses stable isotopes to measure the turnover of Tau proteins in the central nervous system. The study is being led by the Bateman lab at Washington University St Louis in collaboration with UCL. We are also hoping to be involved in the OxQuip study in Oxford.



More recently, we've become involved in PSPA's awareness raising campaign, 10,000 Voices, by writing to our local MP. I think it is empowering to help other people by hopefully making GPs and local hospitals more aware of PSP so that misdiagnosis or underdiagnosis can be reduced.

We have an incredibly supportive MP in Chester, who as part of the campaign, wrote to the Health Minister upon receipt of my letter and confirmed back to me within four days, I could not have asked for more! Our MP has yet to have a response from the government but I would encourage as many people as possible to lobby their MPs so our 10,000 Voices are heard – we are not going away!

In addition to the support we've received from PSPA and our local health services, we are both members of Rare Dementia Support (a UK based service led by the UCL Dementia Research Centre) which is open to people living with rare dementias or related conditions like PSP, and their carers, providing support on a one-to-one and group basis. My husband has particularly enjoyed participating in the RDS Creativity Club which has helped him to



rediscover his talent for sketching and painting in an incredibly warm and supportive environment online.

Our Local PSPA group also encouraged us to contact our local hospice in the spirit of "living well" with PSP, which they certainly encourage us to do and are a very useful source of support and advice.

I would warmly recommend to anyone adapting to life with PSP or CBD to become your own advocate and healthcare recruitment officer. PSPA is a fantastic resource and starting point, but be prepared to spread your net far and wide locally and nationally. A surprising amount of support is out there, just be brave and prepared to be a bit creative. Don't be thrown off course if you get an initial rejection from agencies such as the DWP. Stand your ground, state your case and enlist support of PSPA and other voluntary agencies such as Age UK, Alzheimer's Society, Citizens Advice and Carers UK. Get the legal and admin stuff sorted, including Lasting Power of Attorney, writing your will, writing a care plan and discussing your feelings. Then live your life and take as much joy as you can from every day."





## A TOP TEAM EFFORT FROM TALBOT UNDERWRITING

In the last edition of PSPA Matters, Kelly Hooper shared she had successfully nominated PSPA to be the Charity of the Year for Talbot Underwriting, where she works. Here Kelly gives an update on how the Talbot Team have been helping PSPA this year so far.



"When my mum was first diagnosed with PSP in 2014 I felt devastated and completely overwhelmed. PSPA really helped me come to terms with the diagnosis and gave some great advice.

One thing that really helped me during this time was channelling my energy into fundraising for PSPA, knowing I could do something to help benefit others.

This is something I am so pleased to be continuing over the next two years with my colleagues at Talbot, after PSPA was selected as our Charity of the Year for 2021 and 2022.

Our support got off to a strong start with a Valentines Day themed Bake Off in February, raising approximately £450, which was kindly match funded by Talbot to make the total donation £1,137.50. The winning entry, were these delicious looking Chocolate Raspberry Coconut Hearts, submitted by my colleague Craig Brennan (on behalf of his fiancée Claire).

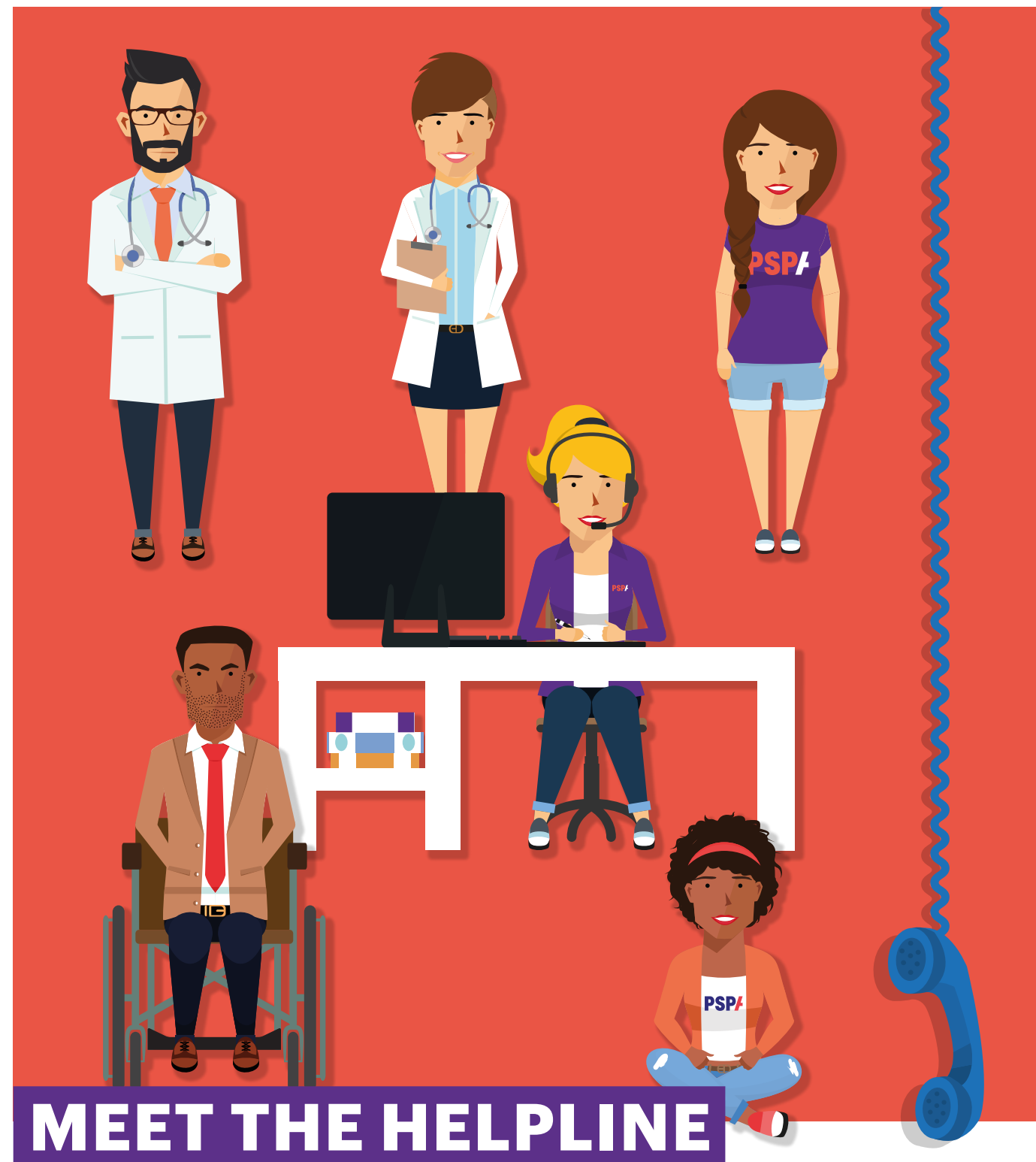
When PSPA launched their 10,000 Voices campaign we were keen to get involved in that too. To help raise funds and awareness, we sold tickets to the 10,000 Voices Raffle and held an Easter Bake Off and family

colouring competition. The activities were received really well. We sold 350 raffle tickets and together with the Easter Bake Off and colouring competition and match funding, raised £1,150, which was fantastic.

Each quarter the Talbot team get together in a big team meeting called the Town Hall. In April, we invited Sarah and Helen from PSPA to join us at the meeting to talk about PSP & CBD, how the charity supports people affected and how people can get involved during the next quarter. People were particularly keen to hear about big challenges like the London Marathon and I was so pleased one of my colleagues signed up to join #TeamPSPA for the marathon in April 2022, straight after the meeting took place.

Moving forward we are planning a Euro 21 football tournament where people get to pick teams to see who comes top of the Talbot league. All teams get multipliers according to who is the least favourite and how far they get in the competition. We ran this for the last world cup and it was a huge success.

I have also sent instructions to everybody encouraging them to sign up to Amazon Smile with PSPA as the beneficiaries as this is such an easy way for the charity to receive donations."



## MEET THE HELPLINE

Many of you will have either telephoned or emailed our confidential Helpline and spoken to one of our four Helpline Care Navigators (HCNs). Our HCNs are trained to support people living with a diagnosis of PSP & CBD, carers, family members and health and social care professionals. All of the HCNs have worked in both health and social care settings and have experience of working in the charity sector before joining PSPA.



Let’s put some faces to the voices on the Helpline as our HCNs tell us a little about themselves and their roles.



**JULES BROWN, HELPLINE TEAM LEADER**  
“I joined the PSPA Helpline in 2014. With a background in the hospitality industry, I always knew I enjoyed talking to people. After my girls were born, I decided to retrain and studied with the OU to learn more about social policy and social care. I had realised I wanted to work in the charity sector specifically with people living with neurological conditions, having met people who were affected by them both within my wider family and socially. I worked for some time in regional information and support at Parkinson’s UK where I first heard of PSPA, not realising that 10 years later I would be working here!

“As part of the Helpline team; listening to, empowering, motivating and empathising with people affected by PSP & CBD is hugely rewarding. Of course, some days are more difficult than others, we can’t always give people the answers or solutions they want, those days require a run at the end of them, to readjust and clear the mind ready for the next day.

“There is, however, never a day where I go home feeling we have not made a positive difference in some small way to someone affected by PSP or CBD.”

**“AS PART OF THE HELPLINE TEAM; LISTENING TO, EMPOWERING, MOTIVATING AND EMPATHISING WITH PEOPLE AFFECTED BY PSP & CBD IS HUGEY REWARDING.”**



**LIZ STURGES, HCN**  
“I trained as an Occupational Therapist and worked for over 20 years in a variety of mental health settings including head injuries and older people. Following this I worked for a dementia charity in an information and support role, visiting people in their homes, and taking phone queries. Before joining PSPA, I worked with people with mild/moderate anxiety and/or depression using low intensity CBT (cognitive behavioural therapy) in a role within the NHS. When I saw the Helpline Care Navigator job advertised with PSPA I realised I missed working in the voluntary sector and applied. The HCN role drew on various strands of my previous working life

“I enjoyed my interview and knew I would like working with the team. The role can be very satisfying when you can support people to access services or benefits, or help them to understand a condition of which they have never previously heard. “In my role there is always a sense of “job well done” if the caller tells you that they feel better having spoken to you, or you have helped even if all you have done is listened.”



**CATHY MOUGHTON, HCN**  
“I joined the voluntary sector on returning to work after having my children and I find it very rewarding. I have worked in information and support services for various charities helping people with disabilities, their family and friends for over 25 years. I believe strongly that people need to be given correct information to make informed decisions. On the PSPA Helpline it is so important to listen and provide information and support that is specific to the person calling and, in a way, they can understand. A lot of time it is just the listening ear that is so vital and for the person to be speaking to somebody that has knowledge of the conditions. I also really enjoy being involved with the Local Groups and getting out to meet the people we support when we are able to again.”



**DEBRA RUDDOCK, HCN**  
“I moved to London from Yorkshire aged 16 to work on a youth training scheme. I worked in a school for children diagnosed with special educational needs, after a year I was supposed to go back to Yorkshire but I forgot as I was enjoying the scheme so much.

“My career has always been in the health and social care industry from teaching children and adults with learning disabilities, to setting up new forms of day care for people living with dementia, as well as care work for both adult social services and the private sector.

“Before joining PSPA I had recently worked in the information service for Age UK. I enjoy learning new

things and extending my knowledge. Like a lot of people, I had not heard of PSP & CBD before I joined the Helpline team. It has been a learning curve and I have loved every minute of it. PSPA has such brilliant and knowledgeable people working here that no question is silly, and they are all very supportive.

“I enjoy listening to people and as we don’t have a magic wand just listening and being there at the end of the phone for them, I feel helps. It is not always about the diagnosis and you learn something new every day.”

**CONTACT THE HELPLINE**  
From 1 July we will be beginning a six-month trial of extending the Helpline hours. From this date, our Helpline will be available from 9am to 9pm, Monday to Friday. Please do take advantage of these extended hours by contacting us on **0300 0110 122** or email **helpline@pspassociation.org.uk**

Our HCN’s can provide you with more information about the PSPA Support Grants  
**[www.pspassociation.org.uk/information-and-support/for-professionals/support-grants/](http://www.pspassociation.org.uk/information-and-support/for-professionals/support-grants/)**

In addition, we have recently launched a new voice banking initiative with SpeakUnique, offering funding to access their services. For more information visit **[www.pspassociation.org.uk/information-and-support/pspa-voice-banking/](http://www.pspassociation.org.uk/information-and-support/pspa-voice-banking/)** or contact the Helpline.

Each of the HCNs is responsible for proactively keeping in touch with people living in a certain area of the UK, see the map on the back of this edition to find out which HCN looks after your area.

The Helpline team will also be growing as we are hoping very soon to be joined by a new team member growing our team to five HCNs.



# 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 a Local Group.
- 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-5pm and 7pm-9pm.**

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

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