

# PSP+ MATTERS

WINTER 2022



## ALSO INSIDE

**Choices  
for future  
treatment  
and care**

**Volunteering  
for PSPA**

**A guide to  
days out**

**NORAPS  
research  
study.**

# RIDING ACROSS BRITAIN FOR DAD

# WELCOME



**Belated New Year wishes to all of our readers. I hope you enjoyed a lovely festive season, creating memories with your family and friends.**

**Here at PSPA, we are excited to be back and moving forward with plans for 2022 and beyond,**

**with our new CEO Rebecca Packwood leading the way.**

I know the team are really looking forward to getting back out into communities, meeting you all face to face again at fundraising events, Support Group meetings and Family and Friends Days. You can pop some upcoming dates in your diaries by reading updates on pages 38 and 39.

To support this work, we are keen to recruit more volunteers to join our team and help provide much needed support to people living with PSP & CBD. This support will be extended locally later this year, thanks to the development of a new volunteer-led service, the PSPA Link Volunteer Service. Read more about this and other volunteering opportunities on pages 20 and 21.

Spending time with family, whether over Christmas or during holidays, can help bring important conversations around Advance Care Planning and your goals and priorities when living with PSP or CBD to the forefront of our minds. If you need some guidance on how to start these conversations, our informative article starting on page 14, will help.

We also share tips for organising days out with your

## WHERE THERE'S A WILL...

**By working together, we can improve the quality of life of those living with PSP & CBD and ultimately find a cure.**

**However, we need your help.** Once you have considered your loved ones, you could make a huge difference by helping us to beat these devastating diseases and to improve the quality of life of those affected.

Please leave PSPA a gift in your will so together we can stop PSP & CBD in their tracks and support people with the diseases to live well and independently for as long as possible.

**YOUR LASTING LEGACY COULD MAKE HISTORY.**

loved ones, to help you make plans for the spring and summer time.

As always, PSPA Matters provides a great forum for sharing personal experiences of PSP & CBD as well as motivation for taking on fundraising challenges such as the London Marathon or Great North Run, gaining support and aiding research via brain donation.

Professor James Rowe's team also share an interesting insight into a current research study taking place in Cambridge and Southampton called NORAPS on page 10.

We hope you enjoy reading this edition of the magazine. The next edition will be coming out in the summer and Rebecca will be taking over the reins of welcoming you to each edition.

Thank you for your continued support to PSPA. Your help makes everything we do possible.



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



**For more information please email**  
**[fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk)**  
**or call 01327 322414**

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### THANK YOU FOR SUPPORTING THE CHRISTMAS BAUBLE APPEAL

Our 2021 annual Christmas Bauble Appeal featured the story of Janice and John, their love of entertaining and experience of PSP. As you can see below, the PSPA Christmas tree was packed full of heart-warming messages from our supporters to their loved ones. Thank you to everyone who dedicated a bauble and donated to the appeal. We are pleased to confirm the appeal raised more than £12,000 to help continue to fund our vital services and research to further our understanding of PSP & CBD.



### COMMUNICATION ACCESS SYMBOL

Have you heard about the Communication Access Symbol? This great idea was created by the Royal College of Speech and Language Therapists in partnership with charities to help companies learn more about accessible communication and how best to support their customers.

Speech problems are common with PSP & CBD and it can be very frustrating trying to make yourself understood when talking to your bank, companies, sales assistants etc. Having someone who understands and has the patience to listen helps people with communication issues remain confident and independent.

Once businesses and organisations have taken part in the appropriate training, they can display the Communication Access Symbol, demonstrating support for those customers who may be experiencing communication difficulties. You can find out the businesses who have the Communication Access Symbol by visiting [communication-access.co.uk](https://communication-access.co.uk)

Why not encourage the businesses you deal with or know to sign up for the training? It's FREE.



### SUPPORT WITH NAVIGATING GRIEF

Grief can feel overwhelming but you don't have to face it alone. Support navigating grief is available from a number of sources including your GP and also the GriefChat service, which is available via our website.

GriefChat offers free and confidential online support from qualified bereavement counsellors. As well as providing support and reassurance, GriefChat can also provide information and signposting to services local to you.

To access GriefChat via the PSPA website, please visit [pspassociation.org.uk/information-and-support/living-with-psp-cbd/useful-organisations](https://pspassociation.org.uk/information-and-support/living-with-psp-cbd/useful-organisations) and the chat box will appear in the bottom right hand corner of your screen.

### HOW YOU CAN HELP

If you are a family member or a friend of someone living with PSP & CBD, you may feel at a loss of how you can help.

Often, channelling your energy into fundraising or volunteering can help you feel you are doing something to support your loved one and raise awareness of PSP & CBD too.

Find out how you can make a difference by requesting a copy of our 'How you can help' leaflet by emailing [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

### CINEMA EXHIBITORS ASSOCIATION CARD

For the film buffs amongst you, whilst watching DVD's and Netflix has been great over the last 18 months, you just can't beat going to the cinema for the big-screen experience. Did you know that the Cinema Exhibitors Association (CEA) card entitles the holder to one free ticket for the person accompanying them?

The cards are easy to apply for provided you are in receipt of Attendance Allowance (AA) or Personal Independence Payment (PIP) and 90% of cinemas in the UK are part of the CEA card scheme. For more information and to apply for a card see their [websiteceacard.co.uk](https://websiteceacard.co.uk)



### GIVE A VOICE RAFFLE

Following the success of our 10,000 Voices Raffle last spring, we will be launching a new raffle this March. The Give A Voice Raffle will help PSPA fund more awareness raising activities as well as to aid the continuation of our information and support service.

Prizes for the raffle include £500, £250, a luxury hamper and a beautiful hand painted hummingbird montage. Tickets will be posted out to everyone who has signed up to receive raffles by post. If you haven't signed up to receive raffles yet, you can do so by calling **01327 322414** or emailing [fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk)

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

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





## WELCOME TO THE TEAM!

As part of our ongoing commitment to improving the lives of people living with PSP & CBD, we have recruited and welcomed a number of new staff in recent months, and also a new Trustee.

Here, our new team members share with us how their previous experience will help us move PSPA forward as well as what they are looking forward to most in their new role.



### REBECCA PACKWOOD – CEO

I joined PSPA in November 2021, after seven years as Chief Executive at the charity Age Exchange. Here I led the charity through an expansion of its specialist dementia and carers support work and a merger with a large social care charity.

I come from a background of leadership in the charity sector including time as the Head of the CEO's department at the NSPCC as well as periods at Housing Associations and Local Government. I am very committed to partnership working and coproduction as a way to transform people's lives and I believe strongly in the independence of the voluntary sector to maintain its creativity and innovation.

There are so many opportunities for PSPA to have an impact on the lives of people living with PSP & CBD. I'm looking forward to building on the already excellent work the team are doing and to maximise new opportunities to improve research, diagnosis, support and treatment.



### HELEN HOLMAN – HEAD OF FUNDRAISING

Hello! My name is Helen Holman, and I am PSPA's new Head of Fundraising. It's exciting working for PSPA, we have big ambitions for 2022 and beyond. I have a broad experience of fundraising with

a background in community, events and gifts in wills fundraising spanning over 20 years which I hope I can use to help us grow income and services for those fighting PSP & CBD.

As I start this role, I want to first acknowledge those who have already done an amazing job of fundraising for us, thank you for all you have already done.

Everyone can get involved. If you would like to come alongside to raise awareness, and fundraise do come and join **#TeamPSPA**. There is so much you could get involved with, from bake sales to challenge events. For further information drop me an email at **[fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk)** I do look forward to having a chance to meet some of you soon.



### KELLY WILDE – HELPLINE CARE NAVIGATOR (NORTH OF ENGLAND)

I am honoured and excited to be joining the PSPA team. I am looking forward to meeting, supporting, and offering a listening ear to individuals affected by PSP & CBD.

I have always known that helping people was what I wanted to do. After graduating in Criminology and Psychology, I fulfilled a goal of becoming a Prison Officer. I realised that to really help people they needed support upon release, so I joined a charity working within the probation service offering rehabilitation support.

After many years, I decided on a career change, I joined Adult Social Services where I enjoyed working with people to create support plans that promoted their wishes and independence, completed referrals to professionals and services and offered support and guidance. When I am not working, I love spending time with my 10-month-old daughter, husband and family from dog walking to theme parks.



### ANNALISA CASARIN – RESEARCH COORDINATOR

Hi, my name is Annalisa Casarin. I am an Italian medical doctor and researcher, and PSPA's new research coordinator. In my new role I will endeavour to implement the charity's research strategy to make the

funding you donate fruitful in terms of impact and benefits for both patients and carers.

I am familiar with PSP since my mum was diagnosed in 2014 and fought her battle until the end. I am glad to have the opportunity to honour her in helping to find solutions for living a better life with the condition. The research studies PSPA funds explore potential treatments and a cure for patients with PSP & CBD and your input will be greatly appreciated. Your experience and participation in research might benefit you and certainly will benefit others in the future. For more information drop me an email at **[research@pspassociation.org.uk](mailto:research@pspassociation.org.uk)**. I look forward to collaborating with you and informing you of our progress.



### ALISON GOOLD – TRUSTEE TREASURER

I am very excited to have joined the PSPA Board on 1 October as the Trustee Treasurer.

I am a Chartered Accountant with a wide-ranging executive career in financial services with a particular focus on investment management.

I have a wealth of experience gained across a number of institutions from large multinational corporations including BNP Paribas, Abbey National and NM Rothschild to smaller niche investment management businesses. I will bring a solid understanding of accounting, financial oversight, risk management and corporate governance to the charity.





## A DRIVE DOWN MEMORY LANE

To help raise awareness of PSP & CBD, Mike Thomas drove his mobility scooter around part of the Brands Hatch circuit on Wednesday 1 December. Here his wife Pat shares details of Mike's PSP diagnosis and where the Brands Hatch idea came from.

"Six years ago, Mike started falling over more backwards than forwards for no apparent reason or so we thought, he never suffered from dizziness or headaches. Each time I would help pick him up and we just carried on whatever we were doing either working in the garden or doing DIY. He always said he was ok. We had been renovating our house and garden for a few years so that when we both retired we could enjoy our home with whatever dog we had.

I worked as a day centre manager for AGEUK and we entertained the elderly clients at home and held lots of summer parties. Mike played a big part in my work and for several years. He would play the Christmas day Santa to hand out the presents. We both did so much for the elderly. We also did lots of fundraising for three local dog rescue homes as we

always had rescue dogs that had medical issues and nobody wanted.

As Mike kept on having the falls over the oncoming years, and at one time 12 in one month, we kept going to see our GP. I asked for Mike to have a brain scan especially as he had already sustained a traumatic brain injury on the left side due to a motor racing accident in 1978 (before I knew him) at Goodwood which resulted in him being in a coma for two weeks. When he came out of the coma he had to learn to walk again as he had forgotten how to do that and lots of other things he had to start over again. Eventually Mike made a good recovery and was able to go back to work. He did remember his love of racing but sadly he was not able to race on the motor racing circuit anymore.





He loved to build and race his slot cars and still has a passion for that but he has had to give that up as well.

Mike sometimes had a problem with his walking and in 2018 he had to start using a walking stick to give him support and confidence. We are both very positive thinking people and whatever life throws at us we deal with it together. After two brain scans it was first thought that Mike had Parkinson's Plus but as he was showing more distinctive symptoms he was finally in 2019 diagnosed with PSP. I have worked in care for 36 years and have never heard of it so I started doing research and sadly Mike matched all the symptoms of PSP.

Mike had to retire earlier than we had planned and I retired in 2020 to be his full-time carer. We had planned where we were going to travel and what we were looking forward to doing in the first five years of our retirement. Unfortunately all those plans went out the window and now we just take one day at a time and try to cope as best as we can. Over these past years when Mike has fallen he has split his head open several times so in April this year I managed to get him a padded safety helmet and what a life saver that has been. He does not fall as much now because he uses the wheelchair more.

Our two Dachshunds Lola and Benji give us both lots of pleasure and Lola is clearly the nurse and guardian of Mike, the minute he moves she is there walking at a snail's pace with him. Whereas Benji just looks and the look on his face says 'I won't get up, Lola has got it' so he just goes back to sleep.

We have all our affairs in order as I am the organised one and we discuss everything together. We both know that there is not a magic wand for PSP but



whenever we can try to fundraise and make people aware of the illness we will. During lockdown I changed and decorated my summerhouse into a vintage tearoom and when we were allowed to socialise I did afternoon teas to raise money for PSPA.

I got Mike a mobility scooter and he came up with the idea that maybe he would be able to drive it around the small circuit at Brands Hatch which is not far from us. I did not say anything to Mike but I got in touch with Brands Hatch and was so pleased after they gave Mike permission to drive there again even on a mobility scooter. When I told him, he was so thrilled and has not stopped talking about it.

Mike showed me a black and white video of him winning a race at Brands and of him going to collect his prize in 1976. On 1 December, it may not be the same atmosphere that Mike had on that day but I know when he will be dressed in his Santa suit and driving at Brands it will bring back happy memories and give him a whole lot of new memories too. "

Mike drove his mobility scooter around the Brands Hatch circuit on Wednesday 1 December, raising an amazing £1,753 plus Gift Aid, in the process. Thanks Mike!

You can support Mike Brands Hatch Santa Dash at [justgiving.com/fundraising/mikethomaspsp](https://justgiving.com/fundraising/mikethomaspsp)



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## **THE NORADRENALINE FOR PSP SYNDROMES (NORAPS) CLINICAL TRIAL – A FRESH APPROACH TO THE TREATMENT OF NON-MOTOR SYMPTOMS IN PSP**

Currently taking place in Cambridge and Southampton, the study doctor and sub-investigator of the NORAPS clinical trial, Dr Duncan Street, shares with us an overview of the trial and what they hope to achieve.



**“THERE ARE KNOWN NORADRENALINE-BOOSTING DRUGS USED IN OTHER MEDICAL CONDITIONS, THAT INCREASE THE NORADRENALINE AND IMPROVE THE FUNCTION OF THE BRAIN. WE BELIEVE THESE DRUGS MAY HELP INCREASE MOTIVATION AND REDUCE IMPULSIVITY, BUT TO KNOW IF THIS IS TRUE, WE ARE RUNNING AN OBJECTIVE CLINICAL TRIAL.”**

“A new multicentre clinical trial, led by Professor James Rowe from the University of Cambridge, is aiming to treat common and disabling behavioural and personality changes in people with PSP. Behavioural and personality changes are common symptoms of PSP and can persist throughout the course. People may lose motivation (“apathy”), be impatient, or take impulsive or risky actions. Such challenging behaviours can be frustrating to live with and be hazardous when combined with movement and balance problems, because of the risk of more falls and injury. Despite the significant impact that apathy and impulsivity have on the quality of life of people with PSP and their families, they are often not recognised. There are no specific or approved treatments yet, although understanding the problems as part of PSP can help to create a safer and less stressful environment at home.

Recent work from the group in Cambridge has shown that apathy and impulsivity frequently occur together in PSP. This may seem contradictory, but both problems are linked to loss of a brain chemical called “noradrenaline”. This ‘adrenaline of the brain’ is made in a very small part of the base of the brain, no bigger than a few grains of rice, and is sent out across the brain to support brain functions that control behaviour (especially the frontal lobes). The source of noradrenaline is called the locus coeruleus, meaning the “blue spot” in Latin, named after its unusual blue colour. This part of the brain is particularly badly damaged by PSP resulting in low levels of natural noradrenaline in the brain.

There are known noradrenaline-boosting drugs used in other medical conditions, that increase the noradrenaline and improve the function of the

brain. We believe these drugs may help increase motivation and reduce impulsivity, but to know if this is true, we are running an objective clinical trial. We are using a drug called Atomoxetine, that has been shown to help impulsivity in some people with Parkinson’s disease and is used to help children with attentional problems. It has not been used before in PSP.

In the “Noradrenaline for PSP syndromes” study (called NORAPS for short), we are measuring the effect of Atomoxetine over eight-weeks of treatment and compare it to a placebo (“dummy medication”). Everyone in the study receives eight weeks of Atomoxetine treatment and eight weeks of placebo but we don’t know the order of treatment until the end of the trial. A family member, close friend or carer provides information about behaviour changes they see during the trial, while the person with PSP undertakes occasional special memory tests. Regular study visits allow the study’s doctor to monitor for improvements and look out for any side effects. In order to understand why some people benefit more than others, we are asking participants to have an MRI brain scan, including, where possible, special high powered MRI scans that can even see the tiny “blue spot” that makes noradrenaline. People with PSP and their carers can sign up for the NORAPS trial at one of several sites. Currently Cambridge (leading site) and Southampton have started, but new sites are due to open in 2022. If you would like to know more, please contact Hugo Paula, our Cambridge clinical trial coordinator ([hp487@medschl.cam.ac.uk](mailto:hp487@medschl.cam.ac.uk)) for further information. We look forward to reporting back to PSPA Matters on the outcome of the clinical trial soon.”





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## “I WANTED TO DO SOMETHING FOR MY DAD AND THE CHARITY THAT HAS SUPPORTED US”

After his dad was diagnosed with PSP in 2018, Michael Aquilina was feeling powerless as his symptoms progressed. Feeling inspired after getting into running during the lockdown, Michael channelled those feelings into doing something for his dad and PSPA by signing up to run the London Marathon.

“Dad had been feeling unsteady on his feet and what he described as a dizziness for a few years before his diagnosis.

When he first sought medical attention, due to the balance issues and dizziness, the first thoughts focused on it being an ear related illness such as vertigo. Tests continued as dad’s symptoms progressed and it seemed like it was a bit of a trial and error approach. Although of course the diagnosis was shocking, it was also weirdly a relief, to finally know what was wrong.

As dad’s symptoms have progressed, it has been a learning curve for us all as we adapt to the different stages of change. I’ve felt quite lost and powerless at times as it feels there is nothing I can do but watch it happening.

I did run before, but certainly no distance. I got into running during the lockdown, more as something to keep me busy and focused.

The London Marathon was always at the back of my mind, as something for the bucket list and as I began



to reach half marathon distances over lockdown, it started to be an idea that I could do it for my dad and for PSPA.

I didn't tell anyone I signed up initially, just keeping it to myself. After I paid the registration fee I did feel a bit nervous, about whether I would be able to commit to all of the training – it is a solid four to five months of running several times a week. But once I told my close family I felt more determined and I couldn't really back out at that point!

I've found the training has given me a lot of joy and a sense of purpose this year. Seeing and feeling your body get stronger and the miles pass by more easily, builds your confidence and raising money makes you feel like you're contributing towards something too. To start my fundraising, I sat down and wrote my dad's story for my JustGiving page. I asked for my family's thoughts as it is their story too. I hadn't shared it publicly before so when I posted it to Facebook, shared it in WhatsApp groups and emailed it to colleagues, the donations kept coming in.

I've received an amazing response, which was really emotional at first. We have a big family and live in a quite tightknit community so my fundraising page has been shared around a lot and people have been super generous. It has been very touching receiving donations from far and wide and surprising some of the people we have reached, I got a flurry of donations from old colleagues my dad worked with over 20 years ago. I can't thank everyone enough.

I was able to top this up thanks to my mum's tennis club who organised a small tournament to raise money for it. Around 20 players took part and their registration fees have gone towards my fundraising, that was very touching as many involved wouldn't know my dad.

After months of training, I'm was really excited about the marathon. My parents live near to the start line so they saw me set off and they joined me again at the finish line. A number of friends were around the route to help cheer me on and give me a boost at various points too.

If anyone is considering signing up for the marathon, I would say just do it. Don't think about the daunting end goal, break it down into more manageable accomplishments: my first 10 km, first 10 miler, first half marathon, PB times etc. You'll end up reaching new milestones every week which is really rewarding. I've loved the experience!"



**MICHAEL AND HIS DAD AT THE PSPA LONDON MARATHON RECEPTION**



**MICHAEL AFTER COMPLETING THE LONDON MARATHON IN 3 HOURS, 31 MINUTES AND 58 SECONDS**





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## STARTING THE CONVERSATION

Thinking about choices for future treatment and care.

Although important, it can be difficult to start thinking about your future care needs. Unfortunately, as your condition progresses, there may come a time when you are unable to explain what your wishes about care or treatment are, or you may be unable to make decisions for yourself.

Knowing where to start, who to talk to, or what choices you can make, may seem confusing. You might also be worried about how your close family

and friends will feel having this conversation, or that they might not be supportive with what you want. For others the conversation will be easy. There is no right or wrong way.

Having future care plans in place will give you peace of mind. It will also enable people around you to support you and ensure your voice remains heard. Having conversations around these plans, sooner rather than later, will give you time to consider your





## “PLANNING IN ADVANCE MEANT MUM COULD STAY AS INDEPENDENT AS POSSIBLE, FOR AS LONG AS POSSIBLE.” EWAN

options as well as offer you the opportunity to have some control over the treatment and care you can receive in the future. Involving your loved ones, will help them to understand your wishes and why you’ve made those choices. It will also ensure they are not left guessing what you might want, if they are asked to make a decision on your behalf.

Thinking about what is important to you, alongside what someone might need to know if they are caring for you, is a good starting point. Consider everyday decisions:

- Food you like to eat, and choices surrounding your ability to eat and drink
- Clothes you like to wear
- Your values and beliefs about how and where you would like to be cared for
- Your wishes about treatment options. There may be specific medical treatments or procedures you would prefer not to have
- How to manage bank, savings accounts and property
- Who you want to sign or read documents on your behalf, if there comes a time when you are unable to do it yourself.

### IS IT IMPORTANT TO RECORD MY WISHES?

It is helpful to write down your thoughts. This will not only help you to be clear in your mind about your wishes, but it will also help you explain them to your family and friends. Take your time with this process, if it is hard to think about. Come back to it on a different day if needed, don’t rush or force the conversation.

In addition, if you have strong views about how you want your care to look, recording your wishes will

reassure you that your family or next of kin will be your voice and ensure your choices and decisions are made.

### HOW CAN I RECORD MY WISHES?

#### ENGLAND AND WALES

**Advance Decisions** - An Advance Decision allows you to record any medical treatments that you do not want to be given in the future, in case you later lack capacity and cannot make or communicate a decision for yourself. The legal name is an Advance Decision to Refuse Treatment, and it is sometimes called a Living Will or an Advance Directive. If an Advance Decision meets certain requirements, it is legally binding and healthcare professionals must follow it.

**Advance Statements** - An Advance Statement is a general statement of anything that is important to you in relation to your health or wellbeing. It can contain information about your lifestyle, the care you would prefer to receive, and information about what you feel is an acceptable quality of life. Legally, a healthcare professional does not have to follow the information in your Advance Statement, however these wishes must be taken into account when a decision is being made on your behalf.

**Lasting Power of Attorney** - A Lasting Power of Attorney for (LPA) allows you to give someone you trust the legal power to make decisions on your behalf in case you later become unable to make decisions for yourself.

**Health and Welfare** - Your attorney can make decisions about anything to do with your health and



welfare. This can include decisions about medical treatment, where you are cared for and the type of care you receive, as well as day-to-day things like your diet, dress and daily routine.

**Property and Financial Affairs** – Your attorney can make decisions about money and property for you, such as managing your bank account, paying bills, collecting benefits or a pension or selling your home.

#### **SCOTLAND**

**Advance Directive** - Allows you to record any medical treatments that you don't want to be given in the future, in case you later lack capacity and cannot

make or communicate a decision for yourself. Advance Directive is the term widely used in Scotland. In other parts of the UK it is called an Advance Decision and it used to be known as a Living Will.

**Power of Attorney (PoA)** - Having a PoA lets you plan what you want another person to do for you in the future, should you become incapable of making decisions about your own affairs.

**Continuing PoA** - Gives powers to deal with money and/or property. Continuing (financial) powers can be used by the attorney immediately after the PoA document has been registered with the

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**“WE DID LOTS OF EARLY PLANNING SO MUM COULD STAY AT HOME THROUGHOUT, SHE WROTE LOTS OF LETTERS TO FAMILY AND FRIENDS WHILST SHE COULD, AND WE SPOKE ABOUT DEATH AND HER FUNERAL TOO.”**



Office of the Public Guardian (Scotland). If the PoA is only to be used in the event of your incapacity, it must clearly state that the powers are not to be used until this happens. You may wish to add a statement about who should make this decision about your incapacity.

**Welfare PoA** - Gives powers to make decisions around health or personal welfare matters. Welfare powers may only be acted upon after the PoA has been registered with the Office of the Public Guardian (Scotland) and when you have lost capacity to make decisions on matters to which the powers apply.

**Combined PoA** - Gives continuing and welfare powers. The majority of PoAs registered are a combination of continuing and welfare powers. You can choose just one or you can do all of them. These documents will only be used if you can no longer make or communicate a decision for yourself.

More information about making or registering a Lasting Power of Attorney (LPA) can be found at [www.gov.uk/power-of-attorney](http://www.gov.uk/power-of-attorney) information about PoAs can be found at [www.publicguardian-scotland.gov.uk/power-of-attorney](http://www.publicguardian-scotland.gov.uk/power-of-attorney)

### HOW WE CAN HELP

PSPA produces an information sheet, Advance Decision guidance for people living with PSP & CBD. The information in this factsheet can also be used when completing an Advance Directive in Scotland. The factsheet is designed to accompany the Advance Decision/ Directive forms and guidance notes provided for free by Compassion in Dying. The form can be completed online or downloaded from [compassionindying.org.uk/library/advance-decision-pack](http://compassionindying.org.uk/library/advance-decision-pack)

PSPA information sheets are available on our website [pspassociation.org.uk](http://pspassociation.org.uk) or by contacting PSPA helpline Monday to Friday, 9am to 9pm on **0300 0110 122** or email [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)



To hear Ewan's experience of advance care planning, please listen to episode eight of the PSPA Podcast on the Anchor app.





## MUM'S PSP DIAGNOSIS DIDN'T COME UNTIL WEEKS BEFORE HER DEATH

Despite experiencing mobility problems for many years, healthcare professionals struggled to diagnose what was wrong with Perdy Kirkland's mum. In fact, the PSP diagnosis only came a few weeks before she passed away. Here Perdy shares her mum's symptoms and diagnosis journey.

"Mum had been experiencing mobility problems for many years, even as far back as 2007 when she had her first severe fall when she fell whilst showering and broke her back in several places.

The falls persisted but without her needing hospitalisation until April 2013 when she fell downstairs receiving a fracture to her right ankle which required surgical repair. From this point in time mum started moving slower than before and needed more aids to assist her walking and around the house. By summer 2017 her walking was much worse, and she was needing to use a wheelchair to

get around outside the home. By November of that year she could no longer lift her legs to get in or out of the bath leading to her having to buy a mobility walk-in bath.

Mum was seen as a bit of an enigma throughout this time as despite her GP's giving timely referrals to different services such as Neurology, the Fracture Prevention Service and Falls Clinic, they seemed to struggle to diagnose what was wrong.

I got very concerned around August 2018 due to a change in her gait and speech and her legs giving



way. She was referred to the hospital for an MRI where the consultant's impression was that she had a chronic problem stemming from a possible high cervical myelopathy, and on top of that also likely had an anterior circulation transient ischaemic attack.

The MRI scan of her brain showed minor small vessel disease only, and within the expected range for a 72-year-old, with no sign of any previous strokes or any abnormality. I continued to press the GP for answers as mum's decline continued, and she was having Parkinson's type tremors and freezing. We had another referral to a neurologist in January 2019 who noted that she had been extensively investigated by neurology already, and he put the falling backwards down to multisensory dizziness, fear of falling, and gait apraxia. He checked her eye movements which were normal therefore ruling out PSP.

Just weeks later she fell backwards down the stairs and ended up in hospital for 17 weeks. During this time, I met with a junior doctor and we went through the symptoms she was then displaying such as backwards falls, muscle weakness, gait apraxia and swallowing problems.

We discussed a number of different conditions including Frontal Temple Dementia, and Normal Pressure Hydrocephalus. All of which were ruled out over the coming weeks and months.

The Speech and Language Therapist didn't find anything untoward, and she was referred to the Cognitive Neuro Unit in June 2019, where she was diagnosed with Mixed Dementia – Vascular and Alzheimer's.

This diagnosis didn't sit right with me, in part due to mum having been institutionalised in hospital for so long due to declining mobility and with recurring urine infections, but also with my detailed knowledge of mum's medical history. I challenged it at the time with the consultant, and later with the GP trying to get a second opinion – My Gran had dementia, my dad has mid-stage Alzheimer's and mum although a bit slow to respond, was still sharp and memory was pretty good.

By the time Mum was discharged from hospital she was unable to walk or stand on her own and was using a wheelchair. We had a hospital bed and equipment in our living room for her, and she needed two carers to lift and move her at first with a Ross Return, but very soon with a mobile hoist.

Following the dementia diagnosis GP's would normally say any new symptoms were just part of Mum's condition, rather than being seen as something separate. I felt like I was labelled as her neurotic daughter as I was on the phone so often to speak to the GP.

2020 was incredibly tough due to Covid. Hospital appointments were cancelled, our GP was doing everything by phone. During the summer, when the weather improved we privately paid for a Physio and OT to come twice a week to try and help mum regain some independence such as adjusting herself sitting in the chair, feeding, or able to hold onto her drink. The Physio's were experienced in neurological rehab and were concerned with mum's diagnosis and they advised to try getting a referral to Gerontology to review mum's medication.

Mum's PSP diagnosis didn't come until the following year. On 31 January 2021 mum was admitted to hospital with sepsis and pneumonia having developed resistance to oral antibiotics due to frequent infections. 24 hours later the hospital tried to send her home but myself and the carers refused as she was declining and needed more care. The hospital put her on to a temporary general ward whilst we were applying for Continuing Healthcare Funding.

On Friday 5 February I had a phone call from a consultant neurologist. He remembered mum from when he saw her when she was admitted in 2019 and apologised as he was only a junior doctor then and couldn't diagnose her. He went on to say she now ticked all the boxes for PSP.

Two days later I had another phone call to say she was end of life. We got mum home for three weeks and two days. She passed away Sunday 7 March at 10.33pm with my sister and I by her side.

Over those three to four weeks she lost the ability to speak, to eat, and in the last few days the ability to swallow the small volumes of fluid we were trying to give her on a teaspoon. It was heart-breaking. I phoned PSPA for support following mum's PSP diagnosis, and when mum was home and stable. I was able to talk things through on the phone, bounce ideas around, and have a bit of support from someone who was familiar with the disease. Despite it being a difficult time, it was reassuring to be able to talk to someone who actually understood, or who I didn't need to explain things to."



## VOLUNTEERING

Our Volunteers are superheroes and everyday make a huge difference to everyone affected by PSP & CBD.

Our wonderful volunteers help people through our Support Groups, respond to calls on the Helpline, provide education sessions for health professionals, support fundraising events, and support the work of PSPA in many different ways. Without them we could not provide the support we do. We currently have over 150 volunteers, but we need many more.

**Did you know volunteering enables you to -**

- Gain confidence
- Make a difference
- Meet people

- Be part of a community
- Learn new skills
- Take on a challenge
- Have fun!

**Why not join us** – There are lots of ways to get involved. We recognise that time is valuable, so whether you can give your time as a one off or become a regular volunteer we would be grateful for your support. There is something to suit everyone.





## VOLUNTEERING OPPORTUNITIES

### SHAPE HOW WE WORK - NEW ROLE!

The best way for us to understand and deliver what our community needs is to involve those who have experience of living with the conditions. Could you help us shape our work? We are looking for people to be involved in our new Service Committee, take part in focus groups and spread the word about PSP & CBD. There are ways to take part over the phone, face to face or by email.

### HELP TO BRING PEOPLE TOGETHER

Our UK-wide network of Support Groups play a vital part in supporting people with PSP, CBD and their families. They provide a sense of belonging, unity and friendship. For many people, their Support Group is their lifeline.

We are looking for Support Groups Coordinators and Support Groups Helpers for a number of areas across the UK. Whatever time you can give there is any opportunity to make a real difference to those in your local area.



### ARE YOU A WARM, EMPATHIC PERSON WITH GOOD COMMUNICATION SKILLS?

If this is you, then why not join our wonderful Evening Helpline volunteers? Our Helpline volunteers offer support, information and a listening ear to people living with PSP, CBD, their families and carers.

Our confidential Helpline is now open 9am to 9pm and our Helpline volunteers cover from 7pm to 9pm Monday to Friday. If you have four hours a month spare we would love you to join us.

### RAISE AWARENESS AMONGST HEALTH AND SOCIAL CARE PROFESSIONALS

We know that PSP & CBD are rare and little known and that is why we need our Education Volunteers to raise awareness and understanding amongst health and social care professionals and local communities. Could you offer informative talks to interested groups? If so, this is the role for you. The events can be face to face or via Zoom.

### SUPPORTING PEOPLE IN YOUR REGION NEW ROLE!

Living with a diagnosis of PSP or CBD is life changing and at times families may need support to help them through the difficult times. Our new Link Volunteer service can offer this support. Support can be face to face, by phone or email. Help reduce the sense of isolation some people affected by these conditions can experience and volunteer as a PSPA Link Volunteer.



### CHEER ON OUR FUNDRAISERS OR HELP AT AN EVENT

Perhaps you are not able to volunteer on a regular basis but still want to be involved. Why not try 'microvolunteering'.

It doesn't matter if it's for an hour a day or a day a year, we need you to join **#TeamPSPA** as a MicroVolunteer.

Visit our website for information on the different roles **[www.pspassociation.org.uk](http://www.pspassociation.org.uk)** or you can call **01327 356137** or email **[volunteering@pspassociation.org.uk](mailto:volunteering@pspassociation.org.uk)**



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## ALTHOUGH I LOST CARL BEFORE HIS TIME, CARING FOR HIM WAS SO WORTHWHILE

At the end of last year, Sheridan Lawson lost her husband Carl who was diagnosed with CBD in 2020. Here Sheridan shares her experience of caring for her husband during the pandemic.

“Carl was diagnosed with CBD on 13 January 2020 by Professor Rowe in Cambridge. He had been diagnosed with Parkinson’s 18 months previously, but the referral to Cambridge came after the medication Carl was given, made no improvements at all.

He was referred to a neurologist after our GP noticed there was something different about Carl’s walking and restriction to one of his arms. The neurologist ordered an MRI scan and his Parkinson’s diagnosis was made soon after.



Despite his diagnosis, Carl remained very active. He still cycled and got out and about.

When the mobility in his arm got worse, the team at Cambridge suggested we try Botox injections but they didn't seem to have an effect. It continued to get worse until really, he couldn't use that arm.

Despite the pandemic, we were really lucky to fit in a holiday during September 2020 to Swanage, which created great memories we will treasure. His mobility was still good at that point. He could be a little unsteady on his feet at times but he didn't need any aids.

In 2021 we went to Wales for a holiday with our daughter, Amber. Carl's mobility had decreased a bit at this point but he was still able to get out in the day and could handle some stairs using the rail.

As Carl's mobility deteriorated, I began to help him more and more. It wasn't easy, particularly if he fell over but I managed to get hold of a few aids to help take the strain off me and Amber, who often helped to pick Carl up if he fell.

We got a mobility scooter for Carl, which he loved and it was really quite nippy. This enabled us to enjoy many a day out at National Trust locations. We particularly liked Stoke Bruerne and Castle Ashby in Northamptonshire.

We also had a stair lift fitted in our house, which helped immensely when stairs became a bit of a struggle. This was kindly funded by his ex-employers. Our local Council had agreed to fund an Eagle Manga for us, to help when Carl fell over (it is an inflatable device which helps bring the person who has fallen up into a seated position, meaning it is easier for them to get up). But unfortunately, it didn't come in time.

Carl's voice had begun to get a bit quieter, although he was still speaking well. We heard about PSPA's voice banking funding via the magazine and around the same time his SLT mentioned it too.

We successfully applied so Carl could bank his voice with SpeakUnique. It was a bit of a lengthy process doing the recording, each afternoon over a few weeks, but it gave us some laughs when Carl got a few bits wrong.

Although he hadn't needed to use it before he died, Carl was really pleased with how the recording

turned out and it was reassuring to know it was there should he need it. Now he has gone, the recordings bring comfort to me and my daughter. We both downloaded the app and it is so nice to hear his voice again.

Unfortunately, Carl died in November last year. It was quite unexpected, despite his CBD. Although his mobility had deteriorated, he was still Carl cognitively and he was still well.

His legs had begun to swell however, during the last 12 months of his life. He was put on water tablets but they didn't help. We were on the phone to the GP a lot during this time trying to work out why the tablets weren't having an effect and why his blood pressure kept rising. I was disappointed the GP didn't come out to visit, all of our appointments were by phone, and I sometimes wonder if she did, if the DVT would have been picked up earlier.

Unfortunately, the DVT eventually caused a blood clot resulting in a heart attack, which is how we lost Carl.

Carl had been looking into brain donation but he hadn't got around to signing the paperwork. Luckily, as his next of kin, I was allowed to sign on his behalf and so his wishes to aid research with his brain were still carried out. They collected his brain within three days.

Looking back, I'm sad we lost Carl too soon. I feel we could have had another two or three years together. Caring for him those last couple of years though, was so worthwhile and I'm glad we had that time together. I'm keen now though, to raise awareness of CBD and also related conditions which can occur as a result of the loss of mobility, such as DVT. I would definitely recommend that anyone who has concerns about their loved one, pushes for a face to face appointment, particularly if swollen legs continue to be a problem."

A person's legs can swell for a number of reasons. DVT is rare and it is not a symptom of PSP or CBD. Please contact your GP or your neurologist if you are ever concerned about any symptoms you are experiencing.





## CONNECTING PEOPLE LIVING WITH CBD

On 10 March 2021, we launched a new group to help expand our support for people living with CBD.

The primary aim of the group is to provide support and friendship for people living with a diagnosis of CBD. By supporting each other, you can help one another to tackle any issues that may lie ahead. The meetings provide a chance for people living with CBD to meet other people in similar situations, carers to share helpful advice to realise they are not alone. However, the group isn't restricted to just talking about CBD, it should also be a time for everyone to get to know one another too.

"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." Susan.

The group meets monthly via Zoom and meeting dates for 2022 include:

9 March  
13 April  
11 May  
8 June

If you are living with CBD and would like to connect with others living similar experiences, you can join the group by contacting our Helpline on **0300 0110 122** or **[helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)**

**"THANKS FOR ORGANISING TODAY'S MEETING. WE FOUND IT EXTREMELY HELPFUL AND IT'S NICE TO MEET OTHER PEOPLE WITH THE SAME DIAGNOSIS."**



## RAISING AWARENESS IN NORTHERN IRELAND

**Determined to help raise awareness of PSP following her own diagnosis, Christine Ferguson set to work organising a motorbike ride out for her brother-in-law to complete in Northern Ireland. Here Christine's sister-in-law Sharon tells where the idea came from and how the ride out went.**

"My sister-in-law Christine is an inspiration. Born in Northern Ireland, Christine trained as a nurse at the Royal Victoria Hospital, Belfast, before moving to the UK mainland and working up through the ranks of the NHS.

Unfortunately, Christine started developing symptoms of PSP around seven years ago and following investigations, was eventually diagnosed around two years ago. Her condition is now quite advanced and Christine can no longer walk and she struggles to speak and eat. Christine is now largely surviving on a few nutritional supplements daily, and experiences constant pain and requires assistance with every aspect of her life.

Despite this Christine remains cheerful and interested in life. Earlier this year, Christine decided she wanted to do something to help fund research and raise awareness into this awful illness.

Although she knows it won't help her, her dream is it will help others who may be diagnosed with PSP & CBD in the future.

Christine came up with the idea that her husband's younger brother, who has been riding motorbikes since his teenage years, should ride his Harley Davidson Road Glide Special around Northern Ireland in one day, stopping off in each county to take photographs and provide an update. Our family set up a JustGiving page and promoted the ride on social media and in the local newspapers. The ride was carried out on Sunday, 25 July, in blazing sunshine and temperatures in the high twenties. Constant updates were provided on social media and an amount of £1,139 was raised. Christine and her family are delighted with the result and hope this will assist PSPA in their endeavours to support others with this condition."

# MAKING THE MOST OF GETTING OUT AND ABOUT

Planning a day out, a weekend away, a short break or an afternoon spent with friends or family, gives us something to look forward to. The COVID-19 pandemic has without doubt changed the ways in which we spend our leisure time, but with spring around the corner, we should be looking forward to being able to enjoy the warmer weather ahead and venturing out and about more, of course, when we feel it is safe enough to do so.

We know that going out of the house is good for our mental and physical health, planning and looking forward to a special trip, a regular day out to somewhere close by or a simple coffee date with friends can improve mood and encourage positivity. There are lots of activities and venues for days out here in the UK, whether you want to stay local or travel further afield, with many choices, in fact something to suit everyone can be found with a little research and some forward planning.

Living with PSP & CBD might make the planning process a little more complex and you should consider parking and access requirements, however there are plenty of ways to find out what is available. Here are a few ideas of where to find information about what is on offer.



The Rough Guide to Accessible Britain is an online guide with over 200 reviews. It is divided into 10 regional groupings which include a range of attractions some active, some cultural. All attractions are reviewed by a team of writers, all of whom either have a disability themselves or care for someone who does. Reports include essential information such as proximity of disabled parking, wheelchair access and more. The guide is updated each year and can be found here - [motability.co.uk/news/rough-guide-to-accessible-britain](https://www.motability.co.uk/news/rough-guide-to-accessible-britain)



The National Trust is custodian of historic buildings and gardens and the countryside across the UK. They have worked hard to make many of their sites welcoming to visitors with disabilities and access requirements.

Many National Trust destinations will have manual wheelchairs available for loan and some of the larger gardens and parks have powered mobility vehicles or the option to be driven around part of the site by a National Trust volunteer.

The National Trust Essential Companion card makes it simple to visit with one or two carers or companions, free of charge.

More information can be found in the National Trust Access Guide which can be viewed and downloaded from their website here- [nationaltrust.org.uk/features/access-for-everyone](https://nationaltrust.org.uk/features/access-for-everyone)



Euan's Guide is a disabled access review site, they review the accessibility of venues around the UK. Suggestions for planning a day out, picking a last minute place for coffee or lunch and lots more information can be found too.

The website is easy to navigate and almost all reviews are made by people living with disabilities themselves - [euansguide.com/](https://euansguide.com/)





AccessAble have surveyed 10,000 plus venues across the UK, including shops, pubs, restaurants, cinemas, theatres, railway stations, hotels, hospitals and more. AccessAble can help you to find out if a venue is wheelchair friendly or you can check what the disabled access and facilities are like.

They have a great 'Top Tips' section. Their website is clear and easy to use, many of the access guides include photos as well as facts about the venue.

Take a look at their website [accessable.co.uk](https://www.accessable.co.uk)

A free App can be downloaded from their home page or from the App Store or Google Play onto a mobile telephone or tablet to use on the go. Perfect for impromptu days out.

A weekend away, short break or holidays gives us a change of scene, allowing us to relax and recharge our internal batteries. They provide a break from our usual routines and give us the opportunity to discover new places and meet new people.

Thinking about and planning for a weekend break or a holiday can feel daunting and exciting at the same time. Concerns about accessibility, suitability to your needs and travel times can all make the planning stage feel tricky. A good idea is to make a list of the equipment and aids you use to make life easier at home. Can any of these be taken with you? Does where you want to go have availability of these items or can they access them for you? There may be a cost involved in the venue providing them, however if you know this ahead of time you

can include these costs in your budget. If you are planning a holiday in the UK, it may be possible to hire from the Red Cross or a local supplier where you are planning to stay.

There are many providers of holidays which are suitable for people living with access needs. PSPA cannot recommend specific venues or providers as we are unable to review them all. Often holidays and breaks away are recommended by friends and acquaintances, this may be a good thing to ask at a Support Group meeting, as a 'word of mouth' recommendation is often really helpful.

If you have time to surf the internet and are Google confident, putting 'disabled friendly accommodation' into the search bar will bring up a long list of websites showing holiday options both here in the UK and abroad. This provides the opportunity to research and compare what is on offer.

The PSPA Helpline has a list of holiday providers who we know people living with PSP & CBD have used, which we can send to you.

Lastly and most importantly, make sure that you have adequate travel insurance, which is up to date. A list of travel insurers we are aware others with PSP & CBD have used is available from the Helpline. Contact us on **0300 0110 122** or [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

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**“MANY NATIONAL TRUST DESTINATIONS WILL HAVE MANUAL WHEELCHAIRS AVAILABLE FOR LOAN AND SOME OF THE LARGER GARDENS AND PARKS HAVE POWERED MOBILITY VEHICLES OR THE OPTION TO BE DRIVEN AROUND.”**

# RIDING ACROSS BRITAIN FOR DAD

The Lands End to John O'Groats cycle was an event John Redfern always wanted to complete. In 2021, with home working arrangements in place, John finally found the time and motivation he needed to tick the event off his bucket list.



JOHN REDFERN CYCLING







“The Lands End to John O’Groats cycle challenge has been something I’ve wanted to do, since I started cycling eight or nine years ago.

Time has always been the barrier to me doing it before now, I have a busy job and a family and a big challenge like this would mean I would need to be out cycling four or five times a week.

For various reasons, 2021 seemed to be when I would have the time I needed to help me achieve this big personal challenge. One of which included working from home. And another being my dad, who is in the latter stages of PSP.

Dad was diagnosed with PSP around two years ago. He was initially diagnosed with Parkinson’s, two years prior to that, after he began tripping and falling over regularly when he was aged 75 (he is 79 now). As dad’s symptoms progressed it became clear it wasn’t Parkinson’s but PSP instead and as I live close to my parents I have seen the full impact it has had on their lives. So, the motivation pushing me forward, was to fundraise for PSPA for my dad and to also help the charity continue the support they offer as well as the research they fund into learning more about the condition and how symptoms can be managed better.

After getting support from my wife Katie, to invest a lot of time in training and completing the challenge, I signed up during the summer.

I was already cycling on a regular basis, but I ramped up the miles as part of my training in June, July and August, clocking around 150 miles a week, largely heading out in the early mornings or evenings. Although it took a lot of time and was a big commitment, I really enjoyed it.

The event took place in September. It was an organised event called Ride Across Britain, with mechanics, medics and guides available throughout the nine days.

As an added challenge, we camped overnight, and in total we covered 970 miles and 53,000 feet of climbs, across England, Scotland and Wales. The weather was pretty good for the first five days, largely dry and sunny. But as we reached Scotland, it became wetter, but the scenery was amazing. I thoroughly enjoyed the whole experience but I definitely had to push myself on a number of occasions. This included the first day in Cornwall, which was challenging due to all the hills, and also the Lecht

in Scotland which was a long steep climb in heavy rain.

After a few days, I teamed up with a few other similar level cyclists and this really helped during the more difficult points.

Cycling to the finish was really exciting. I was elated I had completed such a big personal challenge. I had also made friends along the way and taken in some fantastic scenery too.

All along I was thinking of my dad and the fact I was fundraising to help a charity too. It was inspiring each day to see the donations come in and the supportive comments as I posted details about each day. In total I raised more than £3,400.

My family were really proud of me for doing the challenge. When I got home, I went to see them and gave my dad my medal. I talked him through the highlights and he seemed to get the general gist of what I did and that I was doing it for him.

I do miss all the cycling. Coming home and heading straight back to work meant it felt I was back to reality with a bump. But I feel really lucky to have had the opportunity to do the challenge and support a charity close to my heart.”

In loving memory of Barry Redfern, whose brave and dignified manner of enduring PSP ended on 6 January 2022.





# VOLUNTEERING IN MEMORY OF GRANNY

After her beloved granny passed away from PSP in 2019, Caroline Woodcock was keen to do something to support PSPA and help raise awareness. Here Caroline shares why she signed up to become an Education Volunteer and started to host Zoom pamper sessions for carers.



"My beloved Granny, Hazel, passed away in May 2019 after years of living with PSP. As with many people, she was misdiagnosed for a long time, but once we got the diagnosis we turned to PSPA and were so grateful for the help and support we were given as a family.

In the autumn of 2019, my brother and two cousins all signed up to run the London marathon for PSPA, in Granny's honour. Now, I am not built for running! However, I wanted to do something to support the charity and also raise awareness of the condition. That was when I discovered the opportunity to become an Educational Volunteer – it was like the perfect role had been written for me and I signed up in May 2020. I couldn't be happier to be part of the team.

In spring 2021 I also became a Lifestyle Consultant for Temple Spa, who are a British luxury skincare brand. Having seen how PSP impacted our family, I knew straight away that I would like to combine Temple Spa with PSPA. I have now run six Zoom Spa Experience pamper sessions for carers of people living with PSP or CBD, and I'm hoping this will become a regular event.

Attendees receive a 'pamper pack' from me through the post, and we then join together on Zoom in the evening and I guide the group through one of our signature facial routines, leaving everyone feeling relaxed and pampered. The last 18 months have shown us all how important it is to take care of our wellbeing - mind, body and soul.

The pamper sessions have been really well received by attendees, with some repeat visits! I'm so grateful to PSPA for helping facilitate the classes, and to be able to offer a break and treat to carers. I know first-hand how important it is for family members and carers to look after themselves and take a break, and the Spa Experience classes offer exactly that.

In addition to running the sessions voluntarily, I am also donating 10% of all sales from the pamper sessions to the charity."

The next pamper experiences will be running on 28 April, 23 June and 25 August at 8pm - if you would like to join one or more pamper sessions, please email [communications@pspassociation.org.uk](mailto:communications@pspassociation.org.uk)



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## SUPPORT FOR CARERS

Caring can be rewarding, whilst at the same time physically and emotionally challenging.

As a carer you may find social contacts decrease and you have less time for leisure, family, and friends, who may not realise the pressures you face or find it difficult to know how to help. This can leave you feeling a sense of isolation and that nobody understands what you are going through.

That is, unless you have the opportunity to connect with other carers who are facing similar challenges and can share experiences, tips and ways to get through the lows. Every carers situation is different but linking up with those in similar situations can be really beneficial.

PSPA would like to set up a virtual carers group to offer this support. The group will specifically be for those caring for a loved one with PSP or CBD. It will give carers the opportunity to get together once a month to gain friendship and support. To talk about

feelings, share experiences and generally discuss things that you may not wish to discuss in front of a loved one. The format will be informal, to encourage people to open up and discuss anything that is on their mind.

The first meeting will be on Wednesday 2 March at 7.30pm. If you can't make 7.30pm you can join at any time up to 9pm via Zoom. This first carers group meeting will be an opportunity to find out when you would like to meet and what you would like to do in the meetings. The meeting is open to carers across the UK.

A few words from a fellow carer can be a lifeline. So, whether you need to share an experience, ask a question or let off steam join the new PSPA Carers Support Group by contacting **helpline@pspassociation.org.uk** or **0300 0110 122**.

# 10,000 VOICES AWARDS

## YOUR 10,000 VOICES AWARDS WINNERS

At the end of the 2021 Awareness Week we launched our first 10,000 Voices Awards to help celebrate the achievements of people living in the PSP & CBD Community.

During November, all the nominations received were judged and winners selected.

**The winners for the 2021 10,000 Voices Awards are:**



**ALWAYS AMAZING  
AWARD FOR SOMEONE  
LIVING WITH PSP  
LAURIE DAY**

Laurie lives life to the full despite a diagnosis of PSP. He is a very positive person, focusing on what he can do rather than what he can't. He

is participating in a number of research studies and has joined the Rare Dementia Creativity Club, where Laurie has discovered a hidden talent for drawing and painting.



**ALWAYS AMAZING  
AWARD FOR SOMEONE  
LIVING WITH CBD  
JACKIE WATTERS**

Jackie is an inspiration for her positivity and encouragement. She is determined to enjoy her family and friends no matter what hand she has been dealt.



**CAMPAIGNER OF THE YEAR  
ELLOISE CHARLES**

Elloise has been busy making some noise about PSP since her dad was diagnosed with the condition. This has included reaching out to her Local MP who wrote to Lord Bethnal on Elloise's behalf to share her dad's experience.

**"Finding out about the award has put a huge smile on my face. I'm continuing to make noise about PSP and won't stop doing so!" Elloise**



**CARER OF THE YEAR  
STEPHANIE REDFERN JONES**

Stephanie became a full-time carer for her mum Teresa who was diagnosed with CBD in 2019. Stephanie ensures her mum the most joyful life she can, always thinking of new ways to support and care for her.





### FUNDRAISER OF THE YEAR CHRISTINE HARRISON

Christine who is living with PSP, took on a hand cycle challenge for the Captain Tom 100 completing 2,000 turns over seven days and raising £2,128 for PSPA in the process.

**"Wow. Christine was quite surprised when I told her but we are both, of course, delighted to hear about the award."** Peter Harrison, Christine's husband



### VOLUNTEER OF THE YEAR CAROLINE WOODCOCK

Caroline signed up to become a PSPA volunteer after her granny passed away from PSP. Initially, Caroline became an Education Volunteer because she was keen to raise awareness of the condition,

but she has also been donating her time to run regular carer pamper sessions too.



### HEALTHCARE PROFESSIONAL OF THE YEAR JADE DONNELLY

Jade coordinates a specialist PSP & CBD clinic in Southampton. She always goes above and beyond to ensure people living with PSP & CBD have the information, support

and care they need. She regularly helps out at Support Groups such as Hampshire, Frome and the Newly Diagnosed Group.



### RESEARCHER OF THE YEAR PROFESSOR JAMES ROWE

Prof. Rowe has been dedicated to PSP & CBD research for twenty years. The impact of his research lies not merely in his 350 publications in leading clinical and scientific journals, but more in the approach to

bringing basic science through to what matters most for patients and families.

**"I was moved and delighted to hear that I had been nominated and given the 2021 Researcher of the Year Award from PSPA. I am so lucky to work with a brilliant team of scientists, students, and doctors not just in Cambridge but across the UK in the PROSPECT network and internationally. And it has always been a privilege to work with people affected by PSP & CBD. Their commitment and support to fight PSP & CBD is an inspiration. Despite the challenges of 2021, they have pressed on supporting research towards the goal of better diagnosis, treatment and cure."** Professor Rowe



### CORPORATE OF THE YEAR AJ FITNESS MK

Aaron Card is the owner of AJ Fitness MK. During the autumn Aaron helped connect PSPA with runners to join the team at the marathon, virtually and in London. He also held a 10-hour massage'athon event in

November, raising more than £600 for PSPA.



### 2021 IN-MEMORY AWARD MAURICE CUTTING

Maurice was a strong-minded family man who always remained positive despite his PSP and tried to do as much as he could himself. He had a great sense of humour and even when he lost his voice,

his family could always get a chuckle out of him. Maurice passed away on 21 June 2021 and £335 was raised for PSPA in his memory.

**"Dad would be beaming to know that he won the in memory award, we of course will never forget him, he'll be forever in our hearts."** Maurice's Daughter

**"FINDING OUT ABOUT THE AWARD HAS PUT A HUGE SMILE ON MY FACE. I'M CONTINUING TO MAKE NOISE ABOUT PSP AND WON'T STOP DOING SO!"**



CARRIE-ANNE AND LACHLAN

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## FUNDRAISING TO HELP SUPPORT FAMILIES LIVING WITH PSP & CBD

Following a family diagnosis, Carrie-Anne and her son Lachlan, 13 years old, were keen to do their bit to support PSPA and help raise awareness of PSP & CBD. Here they both tell us how they sprinted into action during 2021 and raised more than £6,000 between them.

Carrie-Anne said "I found PSPA at the end of 2020 after my dad was diagnosed with CBD. After completing a website form, I signed up to receive as much as possible from the charity, including information, Support Group invites and fundraising details.

I'd never really thought about doing a big challenge but then PSPA circulated an email in March asking for people to join #TeamPSPA for the 2021 London Marathon and it planted a seed in my mind. I'm not a runner. I go to the gym regularly but never really ran much in terms of distance, just an odd five

or ten minutes as part of my routine. So even though it was going to be a bit of a sofa to marathon kind of challenge, I signed up to join #TeamPSPA in April 2021, keen to do my bit for the charity.

I researched training for a marathon and found a great 17 weeks plan which I stuck to religiously. As part of the plan, I had to go out running four times a week; two shorter runs, a longer run, and then Sunday became the big distance run each week. I also worked on my mindset, by reading and using meditation to help visualise myself crossing the finishing line. I was surprised at how well the training



went. I never thought I'd be the sort of person that would talk about going for a short, one or two hours, run. But I was.

I also started fundraising by sharing my JustGiving link onto my Facebook page and my friends and family were really generous in supporting me. It was around September time, as I was coming up to the end of my training plan, that an opportunity came up at Lachlan's school."

Lachlan added: "The teacher mentioned in class the chance to win £3,000 for charity by taking part in the annual YPI scheme presentations. I thought this was a great opportunity to help promote and fundraise for PSPA. Grandad had been misdiagnosed for such a long time and I thought gaining this funding could help other families and maybe stop others going through what our family did.

Normally the scheme would see you giving a presentation about a charity to the whole school. But due to COVID-19, this time it just meant presenting to the YIP committee and school head. The presentation was recorded and shared with others who were involved in the vote.

I had lots of ideas and I'd heard previously some people had interviewed someone from the charity. I thought this was a great idea and wanted to do it myself so mum emailed PSPA, who put us in touch with Helen.

I scheduled in a Teams chat with Helen, which I recorded and interviewed her about the charity, what it does, the impact it has, how any money raised is spent and also about her job.

I created a PowerPoint presentation with an introduction including my personal connection to PSPA, with my grandad's diagnosis, and then included the interview with Helen.

The committee would hear about so many different charities, I think sharing details about my grandad's illness and the support we've received really helped PSPA stand out.

I found out just a couple of weeks later that I had been successful in securing the £3,000 funding for PSPA. I told so many people I was doing the presentation, it felt like there was a lot riding on it, so I was relieved and really happy I had managed to get the funding.

I joked to mum, she'd now have to raise £3,000 for her marathon sponsorship and we couldn't believe it when during the course of the marathon, she did.

Carrie-Anne said: "Lachlan getting the grant for PSPA was a big boost ahead of the marathon.

On the day, the atmosphere was amazing and it was very emotional too.

Lachlan had kindly prepared me a five-hour playlist, so I had music to help get me through the miles. But in the end, there was so much going on, with the crowd, live music and looking out for the PSPA cheer point, that I only listened to the sound track a couple of times.

Every time, a PSPA runner came by, we tapped each other on the shoulders which was lovely and a great support. It was also overwhelming to get to the PSPA cheer point at mile 24.

I had it in my head it was at mile 20, then when it wasn't, I thought it must be mile 22. I was really emotional and ready to see my family when I got to mile 24. It was great to see Lachlan, my husband and some of the PSPA cheerers.

Lachlan added: "I was surprised to see mum looking so cheerful when she got to the cheer point.

I felt a bit like a celebrity when Carol from PSPA asked me if I was the one from Scotland who had raised all the money for the charity. It was great to hear about how the money was going to help provide support for families via an event. She even said I could come as guest of honour, which I definitely will.

Carrie-Anne said: "I finished the marathon in five hours and twenty minutes. I was surprised how well my body recovered. I had heard so much about people experiencing stiff muscles and having a funny walk for a few days, but I didn't have any trouble at all. I did a fair bit of walking that day, when we went out to The Ivy for dinner to celebrate, and sight seeing the next day, so I don't know if that helped my muscles ease before going home.

Lachlan and I feel so pleased we've had these opportunities to help PSPA. We'd love to do more in the future. I've not signed up for the 2022 marathon yet, but never say never."



# ANDREW DECIDED TO DONATE HIS BRAIN SOON AFTER HE WAS DIAGNOSED

Sue Robertson's brother, Andrew, was diagnosed with PSP in July 2018 and quickly afterwards he decided to donate his brain to the University of Aberdeen to aid research into the condition.

Here Sue shares how Andrew's PSP developed, what support they accessed as a family and how he donated his brain to research.

"Andrew was an adventurer and traveller. He spent many years in India, studying the birds of Periyar National Park in Kerala about which he co-wrote a guide book and lived life to the full. He was always so curious, always seeking new experiences and information.

He was fiercely independent and a 'coper', so when symptoms of PSP first developed he just pushed through, thinking they were signs of getting older, despite him only being in his late 60's at the time. Struggling to climb the stairs to his flat and feeling confused were the first signs something wasn't right with his health. Looking back, we think the symptoms began as early as 2014. His diagnosis didn't come until 2018 when symptoms were more evident until he fell in the street and was admitted to A&E.

We wished more was known about PSP as we felt quite alone until we found PSPA. We called the Helpline and shared publications with Andrew's GP and then later with care home staff. We attended some Support Group meetings in Edinburgh too, which was invaluable. I feel I received the most support though from the online forum, HealthUnlocked. Reading about other peoples' experiences made it feel like we were walking side-by-side, as symptoms progressed.

Andrew moved into a care home after another bad fall in June 2019 during which he broke his hip. He received fantastic one to one care there for the first 18 months, at this stage he was still able to stand, move about a bit and communicate. Between his daughter and I we visited Andrew most days and we engaged an end of life doula who established a relationship with him concerning his ultimate demise.

The one to one care was removed in March 2021 and thereafter he deteriorated quite quickly. Andrew died really peacefully in August 2021 with his daughter by his side.

To aid research, Andrew made the decision to donate his brain soon after he was diagnosed. He was referred to Dr Diane Swallow at the University of Aberdeen who came to visit Andrew at home to talk about how brain donation would help research into PSP & CBD and how he could sign up. Dr Swallow had the necessary paper work there and Andrew signed up straight away.

Although Andrew knew donating his brain wouldn't help him, he'd already experienced how difficult the condition could be and he wanted to help ensure, in the future, others didn't have to experience the same thing as himself. Both his daughter and I really supported this choice too. Through our experience, we know how little known the condition is, even with healthcare professionals, and so we were all keen to support anything that would help progress awareness or research."





## BRAIN DONATION FOR RESEARCH

The decision to donate your brain to PSP & CBD research creates a long lasting legacy.

Brain Banks provide a unique resource for researchers, both here in the UK and overseas, enabling them to develop their understanding of PSP & CBD and ultimately informing the search for treatments.

If you decide you would like to donate your brain for research into PSP & CBD, there are a few things you may wish to think about:

- Discussing donating your brain tissue with your next -of-kin and those close to you.
- Discuss your wishes with key medical professionals, such as your GP and ask them to update your medical records accordingly
- Register your wishes with a Brain Bank, there are a number across the UK, details of those we are aware are accepting donations are available from the PSPA Helpline
- When you register with a Brain Bank you will be

asked to give permission for the bank to access your medical records.

- If you decide to register with a Brain Bank and you change your mind, don't worry. You can request to come off the donor list by contacting the Brain bank you registered with.



PSPA produces an information sheet titled Brain Donation for Research. This is available to download from our website or by contacting the PSPA Helpline on **0300 0110 122** or **helpline@pspassociation.org.uk**



## WE'RE BACK ON THE ROAD

At last, we are able to get back out and see you all again. We have plans in place to resume 'business as usual'. Fingers crossed. We have missed not seeing you all and it will be good to see old friends and meet new ones.

### SAVE THE DATE!

#### **Saturday 21 May 2022**

Family and Friends Day, 9.30am to 4pm. Join us at The Village Hotel Leeds South, Capitol Boulevard, West Tingley, Leeds, LS27 OTS  
Programme to be confirmed.

#### **Wednesday 20 July 2022**

PSPA Scottish Event. This day will be two separate events at The Stirling Highland Hotel, 29 Spittal Street, Stirling, FK8 1DU.  
8.30am to 12pm, Education and Awareness for Health Professionals  
1pm to 4.30pm, Family and Friends Event  
Programme to be confirmed

#### **Saturday 10 September 2022**

Family and Friends Day, 9.30am to 4pm. Essex.  
Venue and programme to be confirmed.

#### **Wednesday 28 September 2022**

PSPA Study Day, 8.30am to 4pm, Birmingham.  
Venue and programme to be confirmed.





# 2022 CALENDAR OF EVENTS

09.04.22	The Easter 50 Challenge	50km or 25km trek taking in Windsor and Thames Valley
30.04.22	Isle of Wight Challenge	25km, 50km, or 100km trek around the islands coastal path
14.05.22	Jurassic Coast Challenge	25km, 50km, or 100km trek on the iconic Dorset coastline
28.05.22	London 2 Brighton Challenge	25km, 50km, or 100km trek spanning the Capital to the coast
29.05.22	Edinburgh Marathon Festival	10km, Half Marathon and Marathon routes available
29.05.22	RideLondon-Essex 100	The iconic 100 mile cycle is back with a new route
11.06.22	Lake District Challenge	25km, 50km, or 100km tre in the beautiful Lake District
25.06.22	Cotswold Way Challenge	25km, 50km, or 100km trek taking in the stunning Cotswold landscape
09.07.22	Peak District Challenge	25km, 50km, or 100km trek starting in historic Bakewell
10.07.22	ASICS 10k	London's favourite 10k race
23.07.22	Yorkshire Challenge	25km, 50km, or 100km trek in the Nidderdale AONB
06.08.22	South West Coast 50	25km or 50km trek through the best of Exmoor's coastline
04.09.22	South Coast Challenge	25km, 50km, or 100km trek along the gorgeous south coast of England
10.09.22	Thames Path Challenge	25km or 50km trek along England's greatest river
10.09.22	Thames Bridges Trek	25km trek across the capital
11.09.22	Henley 10k	Walk, jog or run along the river, starting and finishing in lovely Henley on Thames
11.09.22	Great North Run	Billed as the world's most popular Half Marathon
24.09.22	Chiltern 50 Challenge	25km, or 50km trek. A way to celebrate Autumn in stunning surroundings
02.10.22	London Marathon	The iconic event
Oct 2022	Royal Parks Half Marathon	The most-beautiful of the London Half Marathons with a route crossing through several of the Capital's Royal Parks
29.10.22	Halloween Walk	A spooky walk through London's streets - Half or Full Marathon distance available



SNOWDEN



EASTER 50 CHALLENGE



GREAT NORTH RUN



ISLE OF WIGHT CHALLENGE



JURASSIC COAST CHALLENGE

# 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-9pm.**

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

# PSP

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