

# PSP **MATTERS**

AUTUMN 2019

**DEDICATE A  
BAUBLE TO  
SOMEONE  
SPECIAL THIS  
CHRISTMAS**

**25  
YEARS OF  
PSP**



**"DEDICATING A CHRISTMAS  
BAUBLE IS ONE WAY I CAN PAY  
TRIBUTE TO TONY AND KEEP  
HIM PART OF MY CHRISTMAS."**

# WHERE THERE'S A WILL...

**We believe that with more funding we can improve diagnosis and treatment, with the ultimate goal of finding a cure for PSP & CBD.**

What if your lasting legacy could be a cure for PSP & CBD? Leaving a gift in your will could make a huge difference in beating these devastating diseases forever. Once you've remembered your loved ones, consider being part of the global fight to end PSP & CBD.



**YOUR  
LASTING  
LEGACY  
COULD  
MAKE  
HISTORY.**

[pspassociation.org.uk/fundraising/legacy](https://pspassociation.org.uk/fundraising/legacy)



## WELCOME

We recognise the fight against PSP & CBD is a global one and we have continued to work closely with partners around the world to accelerate progress. This work is happening alongside a growing sense of optimism among PSP & CBD researchers, as described by Dr Helen Ling on page 12 and Dr Negin Holland on page 22.

We continue to invest heavily in research in order to be at the forefront of the global effort to end PSP & CBD. This investment includes the appointment of two important research posts. Dr Wendy Edwards has joined us in the post of Research Coordinator and will help to further strengthen and build our relationships with clinicians and researchers. Wendy will also be supporting Prof Hugh Perry, the recently appointed Chair of our new Research Advisory Committee (page 26). Together they will be working on PSPA's research strategy outlining how we will maximise the impact of money raised by fundraisers and supporters; and recruiting members to the new Committee, which will make recommendations for research projects for PSPA to fund.

In the last edition of PSPA Matters we reported on the £25K award from the Scottish Government, to fund a strategic development role in Scotland to help improve care and raise awareness of PSP & CBD. I'm delighted to announce we have appointed Gill Dickson as Country Manager - Scotland. Gill comes with a wealth of experience in health, education and social care sectors.

With these appointments PSPA is stronger and better able to promote research and improve support for people affected by PSP & CBD.

**Andrew Symons**, Chief Executive

# CONTENTS

- 04 - 05** PSPA NEWS
- 06 - 07** HILARY'S LETTER
- 08 - 09** MYTH BUSTING - BENEFITS AND ENTITLEMENTS
- 10 - 11** FEEDING, OUR LESSONS LEARNT
- 12 - 13** DR HELEN LING, NEUROLOGIST
- 14** TECHNOLOGY TO CONNECT
- 15** VISUAL COGNITION
- 16** MEET CHRISTINA, EDUCATION VOLUNTEER
- 17** FAMILY AND FRIENDS
- 18 - 19** MEET PROF JAMES MOFFAT
- 20 - 21** CHRISTMAS BAUBLE APPEAL
- 22 - 23** DR NEGIN HOLLAND
- 24 - 25** TRIBUTE FUND FOR DAD
- 26 - 27** PROF HUGH PERRY
- 28 - 29** HOSPICE CARE
- 30 - 31** HOW CBD AFFECTS THE WHOLE FAMILY
- 32 - 35** MOVED TO TAKE ACTION
- 36 - 37** CBD ONLINE CARE PATHWAY
- 38 - 39** MEET MICHAEL LEAVER



**DR WENDY EDWARDS**

### MEET DR WENDY EDWARDS, OUR NEW RESEARCH COORDINATOR

We are thrilled to announce the recruitment of Dr Wendy Edwards to the post of Research Coordinator. Wendy has a PhD in biosciences and comes with over 20 years experience working for medical research charities.

Wendy said: "My dedication to the amazing work charities undertake to improve the lives of people living with long-term conditions is motivated by my own personal experience. My son was born with a rare craniofacial condition, often misdiagnosed, and can lead to loss of vision and brain related issues if not picked up.

"When reading about the common misdiagnosis of PSP & CBD I knew I wanted to be part of an organisation focused on ensuring patients receive the diagnosis and care they deserve.

I am keen for the new research programme to not only address the search for better diagnosis and treatments, but to also ensure that people living with PSP & CBD experience an improved quality of life through better care and service provision. I hope you will join me on our journey in developing our new research programme. If you are interested in taking part in research and have not yet completed a register of interest form please email me on [research@pspassociation.org.uk](mailto:research@pspassociation.org.uk)

### FREEPOST PSPA IS ALL YOU NEED

Last year we set up a Freepost address – simply FREEPOST PSPA. That is all you need to write on the envelope. However some people have also included our actual postal address alongside the FREEPOST address. This results in PSPA receiving an extra charge of £2 per letter. So, please remember, if you are using our Freepost address, just simply write FREEPOST PSPA – it may not look like much of an address, but we promise it will get to us!



### SCOTTISH GOVERNMENT GRANT SECURES DEVELOPMENT MANAGER

In the last edition of *PSPA Matters* we reported that the Scottish Government had awarded us £25K to support a new development role in Scotland. We are thrilled to announce that we have recruited Gill Dickson to the role.

Gill has experience of the health, education and social care sectors and has led on roles to make services more joined up for people who

**GILL DICKSON**

need support. She has also worked with neurological charities and the hospice sector. Gill will be seeking to increase the amount of local support for people in Scotland as well as working with our existing local groups.

Gill said: "I have seen how important it is for people living with progressive neurological conditions to have access to timely, joined up services and the difference that can make to their quality of life. I'm looking forward to building new partnerships within NHS Scotland and raising the profile of PSP & CBD to directly influence the care people receive."



### GOODBYE TO MICHAEL SHEPHERD

We wish a very fond farewell to Local Group Coordinator Michael Shepherd who is stepping down from his role. Michael is one of our longest serving volunteers and set up the Pocklington group over 15 years ago. We would like to thank him dearly for everything he has done for people affected by PSP & CBD. Liz Baxter will be taking over the group coordinator role. Liz, whose dad had PSP, has been a helpline volunteer since January 2018.



### SPOTLIGHT ON: NEW SUPPORT GROUP IN FROME

Denise Hunt's mum was diagnosed with PSP after over four years of tests and appointments. Denise wants to help others living locally with PSP & CBD, so decided to set up a new PSPA Local Group so people living in Somerset, Bath and Bristol can meet up, share experiences and information.

In September the group held their first meeting with 10 people attending. Denise said: "My mum suffered a great deal, not just physically, but mentally too. She has endured the frustration of thinking no one believed her, until eventually, after over four years of appointments a diagnosis of PSP was confirmed. This long and exhausting journey to diagnosis is what drove me to become a PSPA Education Volunteer, and is what now drives me to set up a group to provide people living locally with support. Mum pretty much went straight from hospital into a care home. It was a terrible time and I could have really done with the support of

other people who understand the condition.

"Unfortunately PSP & CBD have some cognitive affects that, unless you understand the condition, people find difficult to cope with. It would have been great for Mum to have been able to socialise with people who understood.

"I hope this group offers support, education and a safe place where people can socialise. I have no pre-determined plans for the meetings, but would prefer to facilitate whatever it is that people want from it. The first meeting went well and was a getting to know you session where people shared their thoughts on what they would like from the group. At every meeting there will certainly be tea and cake, always a good starting point!" The next meeting is planned for 22 November.

If you would like to set up your own PSPA Local Group please contact [volunteering@pspassociation.org.uk](mailto:volunteering@pspassociation.org.uk) or **01327 356137**.

## DISCOVERING OUR STRENGTH

**I'd like to share some ideas with readers about how my husband Dick and I lived with his symptoms of PSP, especially in the last year of his life.** My hope is that it might help you. By the time Dick received his diagnosis of PSP in 2018 his illness was already well established and he died peacefully in January 2019.

Reading PSPAs website, using the helpline and the guide provided great help. Following his diagnosis, Dick's attitude was not 'why me?' but 'why not me?' That way of thinking stopped him from feeling sorry for himself. Medication such as Fluoxetine helped to keep his spirits up.

We saw ourselves as a team focused on helping Dick's body work as best it could. This helped us to maintain our relationship as a married couple and not just me as his carer. As his illness progressed, we'd think of one or two good things that had happened each day before bedtime. We didn't think of it as a devastating disease, but just got on with life as best we could and accepted the situation he was in.

We bought a large tablet, as Dick had sight difficulties. He played computer games, looked at the news and photos. I'd go through the *Radio Times* and find programmes he might like. With three sons to help with the technology we were fortunate. Some towns have computer clubs that can help people who are less technologically minded.

When his condition worsened in 2018, we started to have mini adventures, instead of holidays. Rather than walking in the Jungfrau region of Switzerland as we once did, we'd plan our trips out just as carefully as we did our mountain walks. We were lucky enough to live within 25 minutes of the sea, so would go to the seafronts of Worthing and Brighton and imagine we were on holiday, or we would visit local nature reserves that had suitable paths. Look online for 'easy access' trails and you will find county councils and national parks suggested routes. For example, the South Downs National Park publishes 'Miles without Stiles', which are short walks for people with mobility problems.

If you live in a town, try something you haven't done before. Museums, cinemas and theatres should be accessible and because Dick was a wheelchair user, I would often be given a free ticket as his carer. Many places have community choirs set up. Dick's doctor suggested he joined one and it was so uplifting. Warming up vocal exercises were good for his voice and you don't have to be able to read music. As his eyesight deteriorated, we purchased a large print hymn book for when we attended church.

It would take us a long time to get ready to go out and it could be quite tiring, especially if we'd travelled in our car, so





we'd either take a picnic or make time to go to a café and relax. We'd be prepared by researching disabled toilets, along with suitable parking spaces and cafes.

A word of warning - we decided to buy a powered wheelchair, to save me having to push Dick around too much when we went out for the day. The company failed to tell us that the wheelchair wasn't allowed to be used as a seat in a vehicle, as it didn't conform to national regulations. If you do decide to purchase a powered, battery operated wheelchair, or a manual one and you wish to use it as a seat in an adapted vehicle, check it conforms to government regulations: ISO 7176-19. If purchasing a car to take a wheelchair, there are specialist garages where one can buy adapted cars.



I shall always admire my husband for donating his brain to the Queen Square Brain Bank, for research. His neurologist invited him to do so. Dick's legacy is that he is helping research into PSP.

I hope this has encouraged some of you experiencing the difficulties of PSP or CBD. We were fortunate in many ways, as we used our savings and took out a mortgage to build a downstairs bedroom and wet-room, so that Dick could stay at home. As new difficulties emerged, we'd see it as a challenge to deal with. We bought a set of chargeable radios that cost around £20 so if I was upstairs and he needed something, he could buzz me on the radio and speak to me. That gave us both independence.

I was never a very good cook and found it near impossible to make appetising meals, once Dick needed to have them mashed. We adapted by buying them in. It cost money, but it gave me more time to spend with him, the meals were tasty, nourishing and varied.

Finally, in the last year of his life, I saw each day as a bonus, to be celebrated. When he died peacefully in his sleep it was a relief to the family and for him. It was the right time to go. Now that he is no longer here with me, I focus on remembering the good times we had and think about the kindness of so many people who helped us along the way. To those of you who have been diagnosed with PSP or CBD, you deserve admiration for getting on with life as best you can and my thoughts are with you. To those of you who are caring for a loved one, it's surprising what reserves of strength one discovers. As people, we can be quite remarkable, both those with PSP & CBD and those caring for them. Always, ask for help and advice when you feel you need it.

*Hilary Green*

# MYTH BUSTING - BENEFITS AND ENTITLEMENTS

When you or someone in your family is diagnosed with PSP or CBD, there's a lot of information to take in and process. It's understandable that working your way through the maze of benefits and entitlements can feel very daunting. There can also be a lot of conflicting information and myths.

PSPA Helpline is able to support you with information about benefits and entitlements. Our Helpline often receive calls from people confused about what they may or may not be able to claim. Most of the calls are questions regarding non-means tested benefits and entitlements. Here we bust some of the myths around benefits and entitlements and share with you the facts.

## **ATTENDANCE ALLOWANCE:**

Attendance Allowance may be claimed if you are aged 65 or over and need help with your personal care, or need someone to watch over you to make sure you are safe.

## **DID YOU KNOW?**

- Attendance Allowance is paid at two rates - low or high, is tax free and not means tested.
- Attendance Allowance may increase the amount of any means tested benefits you already receive.
- Attendance Allowance cannot be claimed if you already receive Personal Independence Payment.

## **PERSONAL INDEPENDENCE PAYMENT**

Personal Independence Payment is a tax free, non-means tested benefit for people aged 16-64 to help with the extra costs caused by long term ill health or a disability.

## **Personal Independence Payment has two components:**

- Daily living component- for help participating in everyday life.
- Mobility component - for help getting around.



**DID YOU KNOW?**

You can be paid either component separately or receive both at the same time. Each component has two different levels: a standard rate and an enhanced rate.

**MOTABILITY**

Motability is an independent charity set up to help people with disabilities use a qualifying benefit to improve their mobility. The scheme offers cars on lease, powered wheelchairs and mobility scooters.

**DID YOU KNOW?**

- Enhanced rate mobility component of Personal Independence Payment is a qualifying benefit.
- Your qualifying benefit must have at least 12 months still to run on application to the Motability scheme.
- You cannot start or renew a Motability car agreement if you are in hospital.

**HELP WITH YOUR COUNCIL TAX**

Council Tax is property based tax paid to local councils. Depending on your situation, you may be entitled to a discount, or even an exemption.

**DID YOU KNOW?**

A diagnosis of PSP or CBD does not automatically mean you qualify.

**Disability Reduction - Disabled Band Reduction Scheme, to qualify you must meet one of the qualifying conditions:**

- An additional bathroom or kitchen is needed by the disabled person.
- Enough space in your dwelling for the person to use a wheelchair indoors.
- A room (other than bathroom, kitchen or toilet) needed by the disabled person.

**People who are disregarded - people with severe mental impairment.**

- The person must have a severe impairment of intelligence and social functioning which appears to be permanent; and
- Has a certificate from a registered medical practitioner confirming this; and is entitled to one of the qualifying benefits.
- Personal Independence Payment - daily living component and Attendance Allowance are both qualifying benefits.

The person liable for Council Tax has to make the application to their local authority. We are happy to assist with sourcing application forms from local council websites.



**STEPHEN AND  
YVONNE BUCK**

**“WITH THIS  
EXTRA  
FINANCIAL  
SUPPORT  
... WE CAN  
MAKE THE  
MOST OF  
OUR TIME  
TOGETHER.”**

Calling the Helpline resulted in us accessing financial support that has since made a huge difference to our lives.

“The Helpline explained the benefits we could apply for and even arranged someone from the Department of Work and Pensions (DWP) to come to our home and help us make the application. We then received a follow-up call from the Helpline asking if they had visited us. Without the help and guidance from PSPA, we wouldn't be where we are today.

“It is a great comfort to know that there is an organisation that understands what you are going through and exists to provide support and comfort in the face of this disease. From making that initial call to the Helpline, we now have Attendance Allowance for Yvonne, Carer's Allowance for myself and a Blue Badge.”

Download our General Benefits and Entitlements information sheet for more information [pspassociation.org.uk](https://pspassociation.org.uk) or by contacting our Helpline.

**Please note:** We can refer people who wish to apply for Attendance Allowance or Personal Independence Payment to the DWP Home visiting service. This is a free service where a DWP visitor can visit your home and complete the forms for you. To be referred to this service or for more information, please contact our Helpline on **0300 0110 122** or email [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

## FEEDING, OUR LESSONS LEARNED

When Rita Taylor was diagnosed with PSP, husband Glyn, alongside their daughter Angela Thomas created a system to help Rita with her food and ensure, despite swallowing difficulties, she could still enjoy a varied diet. Angela shares their feeding system in the hope it helps others.

“We were faced with the problem of how to give Mum interesting and varied food, without spending the earth. There are some marvellous packages you can get delivered to your home, but they are expensive, even with Continuing Healthcare provision.

“We needed to find a way to provide a variety of suitable and nutritious meals. Over a few weeks we developed a system that served us well. We experimented, learned and best of all – Mum thrived. She ate a very varied diet of meat, fish, vegetables, fruit and desserts, right up until two weeks before she died.

“Mum had always said she did not want PEG feeding under any circumstances. This was difficult for Dad and I, as we would have liked, initially, to have persuaded her otherwise. Those wishes forced us to be creative and led to us devising a method for her to be fed in a way that pleased us all.

“When someone has swallowing problems there is help available from speech and language teams. However, once you get to the pureed food stage, people often feel buying in ready-made meals is their only option, but this is expensive.

“Our number one piece of equipment was the food processor. We used ours so much it eventually wore out! Next I acquired little plastic pots to hold 100g, 75g and 50g. All pots were labelled with the food type and date to ensure a good rotation in the freezer and easy access for Dad.

“We used the larger, square pots for the protein element of Mum’s meals, such as meat and fish. As Mum’s disease progressed we moved on to tinned meat including minced beef in gravy, chicken in white sauce, meatballs, beef stew and corned beef, which mixed very well with tomato. We developed a number of different combinations that were received well by Mum.

“The 50g pots were used for vegetables. We’d cook a big pot of one type of vegetable, then blend it in the food processor. Dad insisted we gave Mum lots of different types of vegetables, and he never wanted her to have them all blended together, like baby food. In order not to have everything sloppy on the plate we’d put the pureed veg into a sieve before putting it into one of the small pots – this drained off most of the excess water and made the veg easier to manage, both in the pot, and on Mum’s plate.

“Some veg worked better than others. Carrots, parsnip, butternut squash, sprouts, green beans, broccoli, cauliflower (to which we often added some grated cheese and a cheesy sauce) were excellent. Pulses were inappropriate, along with peas and sweetcorn, because of the skins. We learnt that courgette, aubergine, onion and leek didn’t work well either. Mushrooms and tomatoes didn’t work well

**“WE EXPERIENCED,  
LEARNED AND BEST OF ALL  
- MUM THRIVED.”**

alone, but could be added to the proteins successfully. We abandoned potato quite quickly – it doesn't freeze well in individual pots and Mum found it difficult to swallow, even when blended with a sauce.

"At first, we'd peel and cook fresh veg, but after a year or so we discovered that frozen veg worked just as well. Dad suffers with bad arthritis in his hands, so this particular discovery was a Godsend for him. Now he was spared all that peeling and chopping.

"We used the 75g pots for either a 'tea-time sized' protein meal, such as macaroni cheese or spaghetti Bolognese (again we used tinned varieties which blended well), or desserts. One of Mum's desserts was tinned peaches or pears. After removing the juice we'd blend the fruit and freeze it in the pots. When defrosted it could be warmed with some custard. The juice was thick and would be used as a drink, thickened further with Mum's thickener.

"Of the milk puddings, we found some worked better than others. Tapioca, would blend and freeze, as would semolina, but rice didn't work very well. We even blended a single portion Christmas pudding with lots of double cream which, amazingly, worked well and gave Mum a taste of Christmas when normally dried fruit was 'off-limits'.

"Each week Dad checked the freezer to make sure he was well topped up with a variety of meals. Anything that was getting low he'd batch cook. When I was there I'd make sure the freezer was as full as possible before I left. Together we had quite the little industry going on in Mum's kitchen – she would have been proud.

"Mum's carers used to love coming into our home to smell the lovely aromas coming out of the kitchen. They were fascinated by the rows and rows of neatly labelled pots cooling ready for the freezer. They continually commended us on our efforts, which was very gratifying.

**"WE MISS MUM SO MUCH BUT WE ARE GLAD WE WERE ABLE TO PLAY SUCH A PART IN MAKING HER LAST YEAR MORE AGREEABLE."**

"Each evening Dad would get pots out of the freezer ready for Mum's meals the following day. To begin with she was having a 100g of protein and four different vegetables, plus a pudding, twice a day – once at lunchtime, then again at teatime. Because we had experimented with so many different varieties of protein and veg there was always a lot of choice. As time went along we had to cut these sizes down, eventually giving her a smaller portion of protein and veg. But with the sizes all organised, it was very easy to adapt the amount she had and we had almost no waste.

"Dad and I felt pleased we could feed Mum good, wholesome, nutritious and varied food. Mum was well fed and even though giving her the food took a long time and a lot of care and patience, it was something she could look forward to, not dread. Okay, so sometimes she would give a great big sneeze and spray a mouthful far and wide, but those times we would laugh our heads off (especially Mum!) and just carry on – mopping ourselves, the chair, her lap, her slippers down along the way, with a smile. Oh, how we wish we could still be doing that now.

"We miss Mum so much but we are glad we were able to play such a part in making her last year more agreeable. Right until the end Mum remained cheerful and her sense of humour never left her."



ANGELA THOMAS



PLASTIC POTS IN A VARIETY OF SIZES



A close-up portrait of Dr. Helen Ling, a woman with dark hair, smiling gently at the camera. The background is dark and out of focus.

## **“I’M OPTIMISTIC AN EFFECTIVE TREATMENT TO SLOW DISEASE PROGRESSION IS ON THE HORIZON”**

Dr Helen Ling is a neurologist who splits her time between seeing patients at Queen Elizabeth Hospital in King’s Lynn and conducting research at Queen Square Brain Bank in London. Dr Ling talks about her research and how it impacts on her work as a clinician.

Dr Ling said: “The potential of research and how it offers hope in unlocking some of the most devastating conditions is what led me to specialise in neurology. While in training, I was fascinated by the diagnostic aspect of neurological conditions that can’t be diagnosed with a simple blood test or scan.

“After completing my neurology training, I became a clinical fellow to Professor Andrew Lees at Queen Square, London. I had the valuable opportunities to not only further develop my clinical skills and learn about neuroscience research, I also studied pathology of the human brain with neurodegenerative diseases at the Queen Square Brain Bank. Under the mentorship of Professors Andrew Lees and Tamas Revesz, I completed my PhD in PSP & CBD research.

“Patients all have their own personal stories leading them to see a specialist. Most patients with PSP or CBD have been experiencing symptoms long before they receive a diagnosis. One of my patients had been to see eight different specialists about his symptoms and underwent multiple investigations in the past four years. The delay in getting a diagnosis meant he was presenting classical and advanced signs of the disease. As soon as he walked through the door to the consultation room, it was clear to me that he had PSP. When I told him he had PSP, rather than feeling devastated, he and his wife were in tears of relief because they finally could make sense of his symptoms. For them this meant at last they knew what they were up against, and that they could now access suitable care and plan for the future.

“Receiving a diagnosis of PSP or CBD must be incredibly hard, but an early, accurate diagnosis helps. Although currently there is no cure for PSP & CBD, regular clinical assessments cannot be overlooked. An important part of my role as a clinician is listening to the patients and their loved ones and offering strategies and treatment to try to make their day-to-day life easier. I also direct people to PSPA, encourage patients and carers to attend support groups and to apply for Continuing Healthcare when the needs arise to help plan for their future.

“In general, multidisciplinary clinics offer a more comprehensive care when compared with an out-patient general neurology clinic which is typically very busy and has relatively shorter consultation time. Ideally, if resources are available, a multidisciplinary clinic functions as a one-stop shop with access to speech and language therapy, palliative care, physiotherapy, occupational therapy and dietitians in a coordinated way at one clinic setting.

“As a researcher I feel privileged to do my part to contribute towards the quest for a cure to these devastating diseases. As a clinician, research is my proactive way to offer patients hope in knowing that the research community across the world is working hard to tackle CBD & PSP.

“My research is currently funded by CBD Solutions. Clinical symptoms of CBD are heterogeneous and accurate diagnosis can be a challenge. Our research findings showed that three in four patients who had received the diagnosis of CBD in life turned out to have a different neurodegenerative condition confirmed by autopsy. We published this finding in *Brain* medical journal in 2010 and outlined the various clinical subtypes associated with CBD as one of the main diagnostic pitfalls.

“We are now in the final phase of a five-year large-scaled study that aims to improve the understanding of CBD pathology. Knowing where CBD pathology begins in the brain and where and how the pathological changes ‘spread’ in the brain as the disease advances is key to the design of effective treatments targeting an early disease stage, ideally even before patients develop symptoms.

“As part of this research study, we identified the brain regions that are affected by CBD pathology at the earliest disease stage: the anterior frontal cortex and the striatum. This finding also led to the understanding

of the earliest network systems within the brain that are affected by the CBD disease process.

“In the second phase of our study, we identified a small group of CBD patients (six out of 124 cases) who had an aggressive form of CBD, with an average survival period from onset of symptoms of three years or less. This was interesting because CBD typically progresses gradually over six to seven years. We do not view CBD as a rapidly progressive condition. The rapid clinical progression in these patients meant that at least half of them were thought to have a different and more aggressive neurological conditions such as CJD (Creutzfeldt-Jakob disease) during life. Their true diagnosis of CBD only became apparent at autopsy.

“We compared the pathological changes in the brains of these rapidly progressive cases with those of typical CBD cases. We found in the rapidly progressive cases the pathology is more predominant in the neurones than in the glial cells (cells located in the brain and spinal cord that provide support and protection for neurones). This is the first time the underlying pathology of rapidly progressive CBD were systematically studied. Up to 5% of all CBD patients may fall within this ‘aggressive’ subtype. This is an important finding because a disproportionate representation of these patients may potentially impact and skew the outcome of clinical therapeutic trials for CBD.

“Mapping the ‘spread’ of CBD pathology is a vital piece of the puzzle in understanding the disease mechanism and the ongoing search for treatment. This is what motivates me every day – contributing to this knowledge base. I remain optimistic that an effective treatment to at least slow the disease progression is on the horizon.”





## NEW TV DEVICE HOPES TO CONNECT PEOPLE WITH PSP & CBD TO LOVED ONES

If you are a carer for someone living with PSP or CBD it can be hard to leave the house. Even leaving your loved one for a short period of time on their own or with new carers can be daunting. A new device may help with this, through enabling the carer to call their loved one through the TV – and directly see how they are doing.

Kraydel has created a device that it hopes will revolutionise home care for people with progressive degenerative conditions. Kraydel's 'Hub' converts any TV that has an HDMI port into a video-calling system. The Hub sits on top of the TV and links the user to their carers and family members through their TV screen. Alongside being able to make video calls, it also has sensors for wellbeing (room temperature and movement), can remind people to take medication, and can send alerts without the need for the person to work a mobile or any other communication devices.

Founder Paul Moorhead first came up with the idea when thinking about how he could use technology to help his mum, who was becoming increasingly housebound. "Our Hub makes it possible for an older person to remain connected to loved ones and carers. We're aware technology is scary for some. That is why we have designed this device to be low tech."

The three-button remote control is based on a simple 'yes' or 'no' answer system, which enables users to easily navigate the system, without any IT skills.

Amer Fasihi, CEO and one of Kraydel's co-founders said: "We wanted anyone old or young, in good health or frail, to be able to use our hub in seconds. Our plug and play device can be set up in two minutes. All you need is Wi-Fi, a plug socket and an HDMI slot on your TV.

"The light and easy to hold remote control has just three large buttons. There's also no need to change between channels – the Hub will automatically take over the TV to tell you when there's an incoming call, so you do not have to switch between HDMI connections. You can accept or decline the video

call with a single click of a button. There's no need to learn how to use a new technology. It's your TV, in the comfort of your own home."

Kraydel is working with PSPA to evaluate how the Kraydel service could help people living with PSP & CBD.

Amer continues: "This is perfect for people who are tech phobic. There's no charging of devices, or any complicated set up of systems. Carers and loved ones can make a call from their smartphone (using the Kraydel app) and then they see the user sitting in their favourite chair, in their own living room. This can be very reassuring if you have to nip out for a short time. You can also send a text that will appear on the TV. Much of the time the users are watching TV anyway so to communicate via the TV makes perfect sense."

Kraydel will be running a small trial and are appealing for people to test the device. If you are interested in testing and feeding back your views contact [interested@kraydel.com](mailto:interested@kraydel.com)

---

**"OUR HUB MAKES IT POSSIBLE FOR AN OLDER PERSON TO REMAIN CONNECTED TO LOVED ONES AND CARERS. "**





## UNDERSTANDING HOW PSP AFFECTS VISUAL COGNITION

**Dr Dan Smith works in the Department of Psychology at Durham University. Dan's team has been awarded funding for a three-year project to develop a more complete understanding of how PSP affects visual cognition.**

Dan said: "I first heard about PSP as a graduate student when I read a paper describing an unusual and devastating disease characterised by paralysis of the eyes. The paper reported a striking result: people with PSP had a problem moving visual attention that was not experienced by people with Parkinson's disease.

"At the time I was doing my doctoral research and the result seemed to have profound implications for our theoretical understanding of attention. What I didn't realise initially was that it might also be important for the purposes of diagnosis. I was keen to explore how PSP affected attention further and as my career progressed I often thought about the condition. One day I spoke to Dr Neil Archibald, Consultant Neurologist at James Cook University Hospital. He had a particular interest in PSP and was keen to collaborate. He put me in touch with PSPA, and together we ran a workshop with patients, carers, clinicians and academics to generate research ideas.

"One issue that was important to everyone was diagnosis. Because PSP is rare and shares many symptoms with Parkinson's disease, a great many PSP patients are misdiagnosed. This is distressing

to patients and carers and can lead to unnecessary prescription of medications with potentially harmful side effects. Out of the workshop emerged an idea for a pilot study comparing mental functions such as attention and memory in people with PSP and Parkinson's disease, with the long - term aim of evaluating whether such tests could be useful for diagnosis.

"Over the next two years we recruited a group people with PSP and another group of people with Parkinson's disease. We asked them to do computer tasks that tested their eye movements, attention and short-term memory. The results of the pilot study were clear: people with PSP could not make any up or down eye movements, and their left and right eye movements were also affected. Importantly, we found impairments in attention and memory that seemed to correlate with the eye movement problems. These results were very promising, and the Dunhill Medical Trust subsequently agreed to fund a three-year project designed to develop a more complete understanding of how PSP affects visual cognition. This project will begin next year, and we hope it will bring us a step closer to finding a cheap, effective and reliable tool for the early diagnosis of PSP."

CHRISTINA WIGG



## “DAVID WOULD BE PROUD OF WHAT I AM DOING”

Christina Wigg started volunteering for PSPA in February, 18 months after her husband David’s death from CBD. Christina talks about the challenges David faced in getting a diagnosis of CBD, and how she wants to help raise healthcare professional’s awareness of CBD & PSP.

Christina said: “David was a dentist and we ran a practice in town. He was just 53 when his symptoms first started, but, of course we had no idea what they meant then. At the time he’d broken his hand skiing so had to take some time off work – he sadly never returned. He started slurring his speech and would remark on how his legs felt funny. A year later he started to experience the alien limb associated with CBD. It took three years for David to be diagnosed. He survived for another four years, before he died peacefully in his nursing home.

“Neither David or I could really comprehend how he would progress with the disease. His deterioration was rapid. I was in denial. Initially, I didn’t think he’d need a stair lift or wheelchair so we didn’t have things in place for when he needed them. Looking back, I wish we’d arranged those things earlier. It got to a point where he had to walk upstairs wearing a ski helmet in case he fell.

“CBD robs you of everything – your sight, ability to be independent and even your personality. David had

just turned 60 by the time he died. He had moved to a nursing home nine months earlier. I felt so guilty about that. I felt like I hadn’t proved myself as a carer, but it became impossible – he needed 24 hour care. The home was old fashioned, but the nurses were wonderful and provided excellent care.

“David had a PEG fitted which gave him an extra ten months and meant he saw the birth of his second grandson. Something we were all very grateful for.

“It was during Christmas I decided to take on some volunteering. I contacted the hospital but nothing really appealed to me. At one of the PSPA’s Local Groups, I heard about the education volunteer role. It sounded really interesting and I could immediately see the benefit of such a role.

“David had so many incorrect diagnoses. I wanted to help people to understand the disease, especially healthcare professionals. My first talk was at Teesside University to psychology students. I was nervous, but shared my story and experience of caring for David.



I couldn't have done it a year ago, but I feel so much stronger now. I really enjoyed doing it and I'm hoping to give a talk at a hospice next.

"I have a busy life, with looking after my grandsons two days a week, and meeting friends, so I don't want to get too tied down. However, the education volunteer role is perfect for me and completely

flexible, so I can easily fit it into my life. My daughter said David would be proud of what I am doing. I think he would be too – and that is a lovely thought."

**To find out more about volunteering contact 01327 356137 or [volunteering@pspassociation.org.uk](mailto:volunteering@pspassociation.org.uk)**

## "CBD ROBS YOU OF EVERYTHING – YOUR SIGHT, ABILITY TO BE INDEPENDENT AND EVEN YOUR PERSONALITY."

### FAMILY & FRIENDS DAY 2019

Over 80 people joined us in Newport for our Family & Friends Day. We were joined by Dr Alistair Church, Consultant Neurologist at Royal Gwent Hospital who talked about PSP & CBD in detail and briefly shared his experience of his centre being involved in the PROSPECT study. Following on from Alistair was Natalie Jones, Team Lead Occupational Therapist in Community Neurology who explained the role of the OT and provided people with ideas on managing everyday living with PSP & CBD.

After lunch everyone had an opportunity to test their knowledge on benefits and who funds what. Our Helpline Team Leader, Jules Brown helped to guide people through this minefield and we hope people went away with a clearer understanding of what is available. Closing the day was Carol from Stressfree Yoga who led a wonderful armchair Yoga session.

**"It is an enormous comfort to know that the support is there as we face this challenge and that you are available with advice or just to listen. Thank you for organising the day it was much appreciated. I found the sessions very useful and informative."**

We're now planning two Family & Friends Days for 2020 and will keep you posted.







## **“I WANT TO FOCUS ON LIVING”**

**Professor James Moffat – Jim to his friends—grew up as a working-class kid in the industrial heartland of Scotland during the 1950s. Life was hard and money was tight. Shillings were used for the gas meter and tokens for the milk delivered to the doorstep. Jim was destined for a job as a miner. What saved him was a gift for understanding mathematics.**

When he retired in 2015, Jim was one of the Government’s most senior scientists, offering expert advice on defence policy based on mathematical modelling. Sadly, during retirement Jim received a diagnosis of PSP. Jim talks about how he has adapted to the limitations imposed on him by his condition and why it is so important to continue to do what you love.

Jim said: “I always had a gift for maths and enjoyed applying it to real-world problems. My brother and I were the first in our family to go to university—catching the bus into Edinburgh every day. After my degree from Edinburgh I won a Carnegie scholarship to do a PhD in quantum theory at Newcastle University from 1971 to 1974—a subject I loved. However, I also wanted to do something useful for society.

“I joined the Ministry of Defence in 1974 at the height of the cold war. From my first day at the Ministry

(located just across Whitehall from 10 Downing Street) life changed. I was no longer preoccupied by normal day-to-day things and my full attention was focused on the pressure steadily building in Europe between NATO and the Russian empire east of the ‘iron curtain’. I was part of a small policy team providing scientific advice to the military.

“While extremely rewarding, after 41 years of work I was greatly looking forward to retirement and spending more time with my wife Jacky and our two lovely daughters. By the time I retired I still felt fit and well, and was starting my new research Professorship in the Department of Physics at the University of Aberdeen - commuting by email! Towards the end of the year, my health started to concern me. I went to the GP with difficulty walking and what I thought was a bad hip. When I explained to my GP how my foot dragged and my feet felt sticky he immediately

suspected it was neurological and referred me to a consultant neurologist.

“I received a diagnosis of Parkinson’s. As devastating as it was, I remained calm. I’m a very logical person and decided to find out everything I could about the condition. By 2017, I’d been taking medication for Parkinson’s for over a year, but it was having no impact on my symptoms. After some research I came across PSP and wondered if in fact, that was what I had. My wife and I went back to the neurologist and asked if the reason the drugs weren’t working was because I actually had PSP not Parkinson’s. He agreed it should be further investigated. The result of those investigations was that I did indeed have PSP. I was told the average time from diagnosis to death was seven years. I’d already unknowingly lived with PSP for four years, leaving me with possibly just three more. However, I also knew I had to continue to live the best life I could.

“In those early days of diagnosis I found HealthUnlocked an invaluable source of information, especially when we were looking at getting a stair lift. Having access to people also living with PSP on practical matters was incredibly useful. However, I find when people talk about dying it’s depressing.

“PSP has taken away my ability to do many of the things I previously enjoyed, like walking. I soon realised to make the most of life I had to adapt to the condition. It was important to me that I continued to use my brain especially now I was denied the alpine walking holidays my wife and I once enjoyed.

“My local hospice has been very good and I go there every Monday to paint. This isn’t something I ever had much time for when I was working, but it’s something I really enjoy. It’s also good to be in the company of other people from all sorts of different backgrounds.

“I’ve also found refuge in my work at the University of Aberdeen where I am currently researching quantum gravity and writing academic papers on unifying relativity and quantum theory. Writing academic books has provided me with a lifeline and something to get out of bed for. I recently applied to the Institute of Physics with an idea for a book on quantum gravity. They commissioned me to write it, with a deadline of Christmas 2020.

“I’m much better in the mornings, so most days I get up at 5am and work on my book until 10am when I have breakfast. We converted a downstairs room into

a sleeping and workspace with attached wet room, large doors looking out onto the garden and my desk and computer. This environment helps me continue to do what I love.

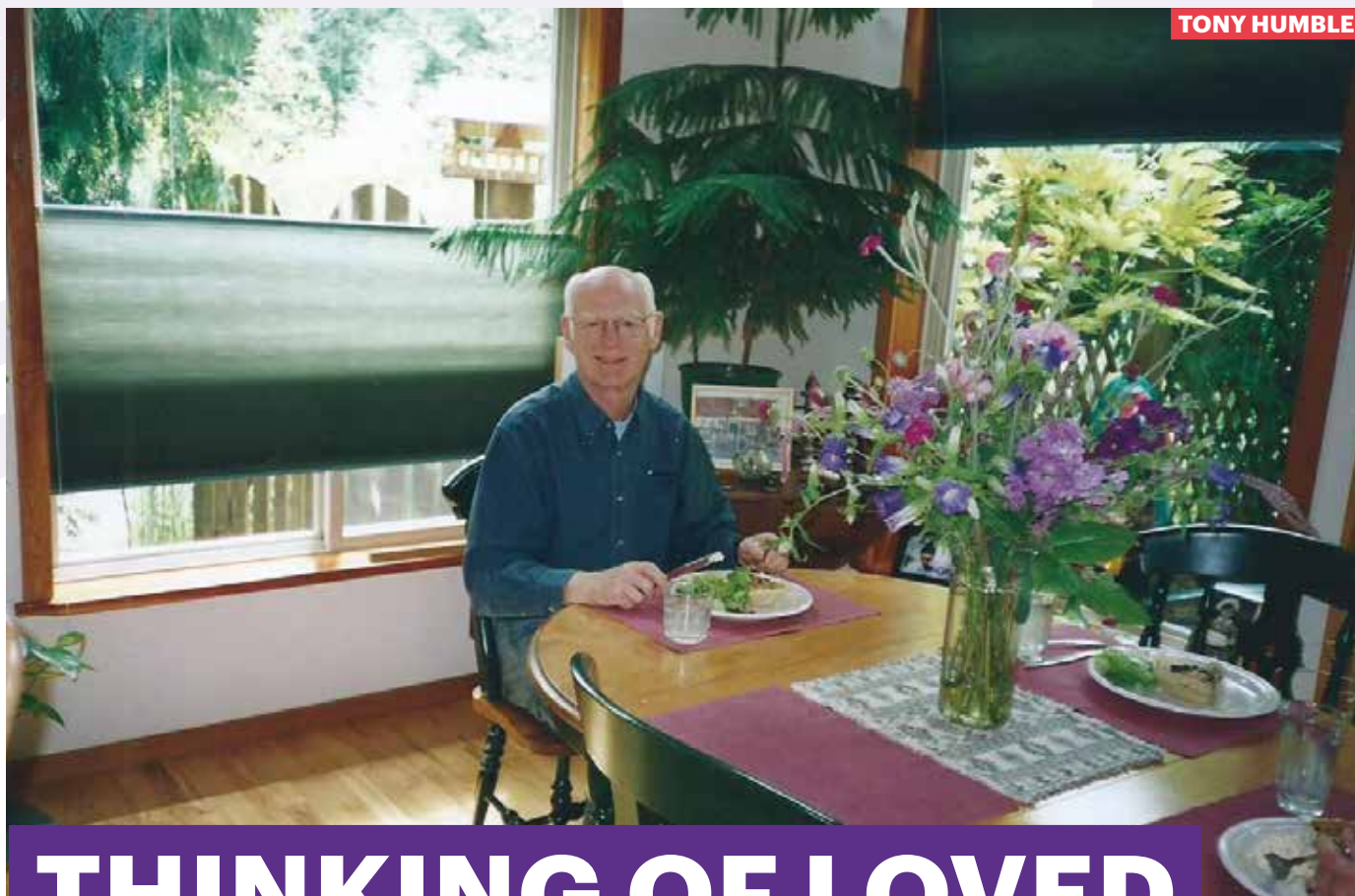
“I also very much enjoy playing chess online. Chess is a game that is very simple in terms of moves, but also very complex. I can play a good game with someone in Hong Kong for ten minutes and then get on with the rest of my day. It is another activity I enjoy that is not yet affected by PSP.

“Maintaining my personal and professional connections keeps me feeling alive. This is how I fight PSP. I can’t and won’t let it get me down. Both Jacky and I take each day as it comes and try not to look too far ahead.

“The principles of medical research are much the same as in physics. Once you know how things work you can improve them. Researchers need to find out why people get PSP in order to understand how to tackle it. Something I very much want to see in my lifetime.”

## “MAINTAINING MY PERSONAL AND PROFESSIONAL CONNECTIONS KEEPS ME FEELING ALIVE. THIS IS HOW I FIGHT PSP.”





# THINKING OF LOVED ONES THIS CHRISTMAS

Christmas is a time for family, and to show loved ones how much they mean to us. Sadly, because of the devastating impact of PSP & CBD, the Christmas period for many families can be difficult.

In the coming weeks nearly 300 people in the UK will learn they'll be spending their first Christmas with PSP or CBD. Like many of you, their lives will be turned upside down. For others, this may be their first Christmas having lost a loved one to PSP or CBD.

Our Christmas Bauble Appeal provides an opportunity to pay tribute to a loved one during the festive season. At the same time it helps to support our work funding research into PSP & CBD, alongside providing information and support to those affected by PSP & CBD.

Every year we are touched by how many of you send in a Christmas bauble to hang on our tree, dedicated to a loved one who is living, or has sadly died

from PSP or CBD. Each bauble hanging on our tree represents much loved mums, dads, grandparents, uncles, aunts, friends or children.

**Ahead of this year's appeal, we wanted to share with you the story behind two names that appear on our special tree year after year.** When Lynne Richards twin sister Lesley died of CBD in 2011, Lynne was determined to raise money for PSPA to help others affected. Every year Lynne donates to PSPA's Christmas Bauble Appeal and shares how it has now become a Christmas tradition.

Lynne said: "PSPA is at the top of our charity list. How could it not be after watching what my twin sister Lesley went through. You don't realise how cruel the





disease is until you see it with your own eyes.

“Lesley and I were very close. I loved being a twin, it meant I didn’t have to do anything on my own. I had someone by my side throughout all the big milestones, like starting and leaving school. Even when we both married and moved to different areas we were still close. I knew she was always there for me.

“The deterioration was rapid. Lesley went from walking around seven miles a day to being in a wheelchair, unable to swallow or communicate with us. After Lesley died, I suggested to my husband Bob that we attend one of the Local Group meetings. Everyone was so kind and supportive. We soon made friends and have attended meetings ever since. Going through a devastating experience like this really shows you how kind people can be.

“Every year we donate to PSPA’s Christmas Bauble Appeal. I think of Lesley often. Even now I catch myself thinking I’ll give Lesley a call. For me, donating to the Christmas Bauble Appeal helps to bring Lesley closer. It provides us with an opportunity to remember her, alongside knowing that our donation will help others. Christmas is a time for family. Lesley is always with us, but by creating a yearly tradition of putting her name on a bauble helps her to be part of every Christmas.

“I see the progress that is being made and I firmly believe that eventually they will find a cure. I’d like, in some small way, for Lesley and I to be part of that effort, so will continue to make sure there is a bauble with her name on it every year.”

Margaret Humble’s husband, Tony, died of PSP in 2014. Ever since his death Margaret has donated to our Christmas Bauble Appeal and dedicated a bauble to Tony.

Margaret said: “Tony liked to keep busy. He was a member of the Rambling Association and would walk most weekends. He was very fit but around 2009 he started to fall. Sadly it was PSP, not that we knew it then.

“It was so tragic to see what PSP did to him - a man so full of life. By the end he couldn’t walk, talk or eat. It was all taken away from him. During those dark times PSPA’s helpline was a tremendous support. I often called for advice. It was just so helpful to talk things over with someone who understood.

“With the help of my daughter and carers who came in three times a day, we managed to keep Tony at home until he died in June 2014. The first Christmas without Tony was especially hard. We had always enjoyed large family Christmases at our home. In the end, we decided to go out for Christmas to a local restaurant. After 50 years cooking Christmas dinner, going out felt very strange, but we got through it. The following year we went out again, but this year I’ve decided to stay at home. I shall get up, make smoked salmon and scrambled eggs and enjoy listening to my ‘boyfriends’, Jack Jones and Andy Williams, on the stereo. I know Tony would appreciate that too.

“The one thing I have done every Christmas since Tony died is dedicate a bauble to him and donate to PSPA’s Christmas Bauble Appeal. It is something I will continue to do, not just for Tony, but also for all those people living with PSP & CBD. After watching what Tony went through I want to be able to help others. Dedicating a Christmas bauble is one way I can do that alongside making a tribute to Tony and keeping him part of my Christmas activities – whatever I end up doing.”

**We will be launching this year’s Christmas Bauble Appeal in November. If you would like to dedicate a gift to someone special, alongside supporting our vital work, simply complete the bauble you’ll receive in the post. All baubles will be hung on a special tree at PSPA head office.**

**You can also give a Christmas gift online at [www.pspassociation.org.uk/christmas](http://www.pspassociation.org.uk/christmas). Here you can either make a simple donation or you can donate and create an e-card to send to a loved one to show you are thinking of them.**



## **“THE UK IS LEADING RESEARCH INTO PSP & CBD”**

**Dr Negin Holland is a specialist registrar in neurology and has recently joined Prof James Rowe’s team at Cambridge as a Clinical Research Associate and PhD student. Negin talks about her PhD study in PSP & CBD and how major advancements in imaging technology is helping researchers to unlock the secrets of PSP & CBD.**

Negin explains: “My interest is in movement disorders, and the variable presentations and causes - it led to my desire to specialise in neurology. I want to know how to modify conditions like PSP & CBD early, and eventually, how to cure them. However, the first step towards treatment discovery is better understanding of the disease. I hope to contribute towards this understanding through my PhD research project that began earlier this year.

“Professor Rowe’s research group is internationally known for its expertise in understanding diseases of frontotemporal lobar degeneration, including PSP & CBD. The group uses various techniques, including brain imaging, to understand the underlying causes of these conditions, their natural history over time,

their genetics, and how they affect memory and thinking. All this leads towards new clinical trials.

“I’m studying the impact of PSP & CBD on the microscopic connections between brain cells (known as synapses). These synapses are essential to the function of the brain, for movement, memory and behaviour. They can be affected by the build-up of junk proteins such as tau in PSP & CBD. Healthy brain cells have thousands of synapses, but the number falls dramatically in PSP & CBD.

“A lot of what scientists know about synapses has come from animal studies, or analysing brains post-mortem. My aim is to use a new method to measure synapses in living patients, using a special type of brain scan

(called PET) and a new injectable 'dye' that lights up the synapses for the scanner. I can then visualise and count synapses, for the first time during life. I will look at the effect of PSP & CBD on synapses, and the impact of synapse loss on brain function, and symptoms. I expect that synapses are lost in some brain regions faster than others, and this difference is one reason why people with PSP differ so much from each other. This will help guide new experimental therapies.

"Soon after I started my PhD in Professor Rowe's group I successfully applied for ethical approval for my project and began recruiting PSP & CBD patients, alongside healthy 'control' participants. The majority of our patient participants come from the NHS specialist clinic for PSP & CBD led by Prof Rowe. Patients come from all over the East of England, and further afield. Many come because they have seen our study details.

"We already have a group of over 50 people taking part. All participants undergo brain scans, along with an up to date medical assessment and memory tests. They have both MRI and PET scans. It'll be a few months yet before I can report on the outcome of the study, so watch this space...

"There has been an increasing number of clinical trials recently, but for disease modifying therapies to have greatest impact they will need to be introduced early in the course of the illness. This makes early diagnosis even more of a pressing matter, and my colleagues in the Cambridge Centre for Parkinson-Plus are working on ways to get earlier accurate diagnosis.

"I'm fortunate to work with such an incredible group of participants, including patients and their families. Despite the physical difficulties caused by PSP & CBD, it is humbling to see how willing people are to take part in research. Many do so as their way of contributing towards treatment discovery, to help those diagnosed in the future. But, we also try to make the research visits interesting and we use the opportunity to keep up to date with treatment and other support.

"One of our participants with CBD recently completed all parts of our study, and was the first such patient to undergo synaptic PET imaging in the UK. I was in awe and humbled by his willingness and tenacity to complete the study. He transferred onto the scanner with our help and tolerated the scans very well. For us as researchers, the participants' comfort and safety is our priority; we are very aware of the time and effort participants put in to make the research succeed.

Our patient participants tell us that research days give them great a day out, as well as the chance to do something themselves to defeat PSP & CBD.

"At Cambridge we hold regular NHS clinics for patients affected by PSP & CBD, many of whom have been referred to us by neurologists from across the East of England and beyond, from movement disorders clinics or memory clinics. We see the full range of PSP & CBD.

"PSP & CBD are very dynamic illnesses, and what we do in clinic reflects this. Getting the right diagnosis is clearly a big step, but it is the start of a long journey. Dealing with the many symptoms as they change, planning ahead to reduce risks and complications, getting help with financial, legal, emotional aspects of the illness, and supporting carers as much as families – there is so much to do!

"PSP & CBD are too often overlooked by funders. They are relatively rare illnesses, but their impact is huge. We have been lucky in Cambridge to have got major funding from the Medical Research Council and philanthropy, but this success was only possible because of the head start given to research projects by PSPA, and the continuing support of PSPA's community. I have no doubt that PSP & CBD can be cured, but it will take a commitment from funding bodies to make this happen soon.

"To people with PSP, CBD and their families I want to say a big thank you. The UK is leading research against PSP & CBD, and we could not do this without your help. Even before a cure is found, there is so much that can be done to maintain quality of life and chip away at the illness bit by bit. This works best as a partnership, between patients, their family, the medical team and community services - I have seen how this can make a big difference to living well with PSP & CBD."

**"I HAVE NO DOUBT  
THAT PSP & CBD CAN BE  
CURED, BUT IT WILL TAKE  
A COMMITMENT FROM  
FUNDING BODIES."**



ALAN AND JOAN BRIGHT



Setting up a PSPA Tribute Fund provides a way for family and friends to remember someone special, and raise money to fight PSP & CBD in their memory. Tribute Fund pages can be personalised with stories and photos of your loved one, helping to celebrate their life. You can also leave messages of support and dedicate donations to their memory.

Joanna Irwin's mum, Joan Bright, has been living with PSP for nine years. Sadly this year Joanna's dad Alan suddenly died. The family decided to raise money for PSPA in Alan's name. Joanna shares how setting up a Tribute Fund provided the family comfort during a devastating time.

"Mum has been told many times that she is at end of life stage. She is blind, can hardly speak, is PEG fed and is bed bound. But she isn't ready to go yet and keeps bouncing back. Watching her progress has been devastating to all of us, especially for my dad Alan. My parents met when mum was 15 and got married when she was 16. They've been together 60 years and not spent a day apart. That was until PSP came into their lives. It got to a stage where

Dad was told home was no longer safe for Mum. She had to move into a nursing home. Initially we had all those terrible feelings of guilt, but she is in the most amazing place by the sea and Dad would visit her every day.

"At the start of this year Dad was diagnosed with bowel cancer. We believed he'd recover but sadly he died in June, just a day before his birthday. It was both unexpected and heart-breaking. Before going into hospital Dad was worried in case something went wrong so we talked about his wishes. As a family we have always supported PSPA and he wanted that to continue. Dad made it clear that he wanted any donations following his death to go to PSPA.

"We carried out Dad's wishes and raised money in his name. At the funeral, instead of flowers we asked for donations. I couldn't believe it when I saw £1,600 had been donated. Dad would have been so proud. The family are so grateful to our wonderful friends and family who very kindly donated to Dad's Tribute Fund. It is a true testament to how much he was loved by all. Mum's nursing home, Well's House Nursing Home also raised money in Dad's name and we are so grateful to the staff for doing this and providing Mum with such wonderful care.

"Setting up a Tribute Fund provides friends and family with something positive to do, when faced with the devastating death of someone close. We certainly take comfort from knowing that the money raised in Dad's name will help others living with PSP."

Your Tribute Fund can help make vital PSP & CBD research possible, all in your loved one's memory. You can make sure people living with PSP & CBD get access to the information and support they need, until the day a cure is found.

If you would like to know more about setting up a Tribute Fund please contact [fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk) or visit our website [pspassociation.org.uk/tribute-funds/](https://pspassociation.org.uk/tribute-funds/) for more details.

#### TRIBUTE TREES

When your fund reaches £2,500 we will invite you to dedicate a tree to your loved one in one of the Woodland Trust sites across the UK.

**"WE CARRIED OUT DAD'S WISHES AND RAISED MONEY IN HIS NAME. AT THE FUNERAL, INSTEAD OF FLOWERS WE ASKED FOR DONATIONS. I COULDN'T BELIEVE IT WHEN I SAW £1,600 HAD BEEN DONATED."**

ALAN AND JOAN BRIGHT







## MAXIMISING THE IMPACT OF OUR RESEARCH SPEND

PSPA is developing a new research strategy outlining how it will maximise the impact of money raised by fundraisers and supporters. Alongside this, PSPA is setting up a new Research Advisory Committee to review and recommend studies for the charity to fund.

We have appointed Prof Hugh Perry as Chair of the new Research Advisory Committee (RAC). Prof Hugh Perry is a Consultant and Neuroinflammation Theme Lead at the Dementia Research Institute UCL.

During his career, Hugh's sat on a number of research advisory boards and funding panels for government and charities in the area of neuroinflammation and neurodegenerative disease. Currently Emeritus Professor at the University of Southampton, Hugh was previously Chair of the Medical Research Council (MRC) Neurosciences and Mental Health Board from 2012 – 2017. He is an advisor to the UK Dementia Research Institute.

*PSPA Matters* spoke to Hugh about his new appointment and how PSPA can maximise its investment in research.

Hugh said: "It's important to appreciate just how underfunded research into neurodegenerative diseases has been compared to other areas, such as cancer. This historic lack of funding is surprising given the economic costs and social consequences of neurodegenerative diseases.

"The UK Dementia Research Institute was established in 2017 as a consequence of Prime Minister David Cameron recognising the importance of dementia research. While this is helping to increase the amount of research within dementia-related areas in the UK, it is still modest compared to the scale of the problem. Dementia-related areas cover a range of protein misfolding diseases, of which PSP & CBD are included.

"It is important to recognise PSPA's role in helping to promote and facilitate research taking place in



institutions and universities, not just in this country, but internationally. It is only through collaboration we will be able to better understand PSP & CBD. The recent International Symposium hosted by PSPA is a good example of the charity fostering this type of collaboration, by bringing together researchers and clinicians to share their work, their ideas and create new partnerships.

“In regard to investing in research there are some key decisions PSPA needs to make. For example, does it spend its money on one or two large grants each year, or does it fund one large grant and then a number of Fellowship grants or smaller grants to help encourage a new generation of researchers with a special interest in PSP & CBD? The research strategy will be important in setting a clear direction for research priorities over the next five years.

“The role of the new RAC will be to review proposals for research studies that might be funded by PSPA. The proposals will likely range from studies addressing a critical problem at the cellular and molecular level that contributes to disease progression, to the more clinically orientated studies focused on improving diagnosis. With each submission the panel will pose two important questions. Is the question the study is seeking to answer an important one and is this study going to improve our understanding of the diseases? The committee will then advise the trustees on the studies to fund.

“In recruiting scientists and clinicians to sit on the panel, it’s important to gather a broad range of professionals with experience in understanding protein misfolding diseases. This area is exceedingly complex. There are a number of different processes involved in the misfolding of protein leading to the slow demise of neurones and glia cells. The literature covering this area is vast and no one expert can be knowledgeable across all areas. Rather, it requires insight from a number of specialists who collectively hold a broad range of knowledge.

“We also need to ensure that research funded by PSPA is not in areas already being explored by large

pharmaceutical companies. There is no need to replicate what they are doing, instead we should be seeking to explore new avenues. Until around seven years ago the focus on Alzheimer’s research was predominately focused on the role of amyloid and tau proteins. The role of glia (non-neuronal cells located in the brain and spinal cord) was under explored. Genetic research into risk factors contributing to Alzheimer’s has shifted the focus onto glia and inflammation. This opened up new avenues for research to focus on. The same situation is likely to be similar for PSP & CBD. There are possibly alternative routes for modifying these diseases. We may not be aware of them yet, but we need to be alert that there are other components than tau.

### **PATIENT POWER**

“One of the most vital elements in fostering and furthering research is patient power. The patient population is hugely important in bringing their condition to people’s attention and pushing it further up the agenda. PSPA has a critical role in bringing together people affected by the condition, their carers and researchers.

“Patients understand what it is like to have the disease. They know what the biggest issues are. They are the true experts of the disease. This is why it is so important to utilise patient’s own insight into their condition. By understanding more about their symptoms, one can gain a better understanding on the different components of the disease.

“I’ve been involved in charities representing very rare disease and seen first-hand how patient power works. Researchers are provided with relatively small grants to conduct innovative projects. Each of those small projects acts as an ambassador for raising the profile of the disease. It fuels people’s interest and potentially sparks off other studies and sources of funding. Small amounts of money often act as a stimulus for more. This is exactly what we hope to achieve for research into PSP & CBD. We want to see the money PSPA invests lead to new sources of funding, so we can finally unlock the secrets of these devastating conditions.”

**“ONE OF THE MOST VITAL ELEMENTS IN FOSTERING AND FURTHERING RESEARCH IS PATIENT POWER.”**



## HOSPICES CARING FOR PEOPLE WITH NEUROLOGICAL CONDITIONS

Hospices can provide valuable support to people living with PSP & CBD. We know many people living with PSP & CBD attend their local hospices for services ranging from art and music therapy, to symptom control.

Increasingly hospices are developing new ways to support people living with neurological conditions. *PSPA Matters* spoke to a hospice in the North East about its work in developing a specialist six week course for people living with PSP & CBD and their carers to promote independence and wellbeing.

Working with PSPA, St Oswald's Hospice in Newcastle upon Tyne, set up a therapeutic group that provides support and information to people in the earlier stages of PSP, CBD and MSA (Multiple System Atrophy).

Jill Lisle, Deputy Day Services Manager at St Oswald's Hospice, said: "Over the last few years St Oswald's has been adapting day services to meet the changing needs of our patients, who are living

with increasingly more complex conditions. The new group allows for care and support to be bespoke to this group of people, in a small and intimate setting of just four people and their carers.

"The group provided the opportunity for peer support, a safe space for individuals to explore the impact of diagnosis and managing change, as well as access to practical support and information to help manage day to day challenges. There were also opportunities to experience 'tasters' of our services, such as therapeutic activities and complementary therapy.

"Feedback from patients and carers has been overwhelmingly positive. They valued meeting staff members from different teams within the hospice,



such as nurses, doctors, physiotherapists, social workers and therapeutic activities coordinators. Patients found practical sessions particularly helpful as adaptations to the home can make a huge difference to help support people with PSP to remain as independent as possible for as long as they can. The sessions have also been a great way to introduce people to the hospice and some of the patients and carers who attended have now been referred to other care services at St Oswald's."

Muriel Mitchinson attended the group with her husband Michael who has been diagnosed with PSP. Muriel said: "When it was first suggested that we attend the course at the hospice Michael was initially frightened and didn't want to go. As soon as we got to St Oswald's though, we both felt very differently.

"We learned quite a lot practically, and the support from the Hospice has confirmed a lot of things I already knew. Most importantly, it made Michael and I realise that we aren't alone – there's other people in a similar situation. It was so helpful to share stories between one another.

"Although very reluctant initially, Michael enjoyed the group, which included an arts and crafts session. We have even talked about Michael using St Oswald's services once a week, which would be a great break for both of us."

If you would like to find out more about accessing hospice care in your area contact our Helpline on **0300 0110 122** or email **helpline@pspassociation.org.uk**

---

**"WE LEARNED QUITE A LOT PRACTICALLY. MOST IMPORTANTLY, IT MADE MICHAEL AND I REALISE THAT WE AREN'T ALONE – THERE'S OTHER PEOPLE IN A SIMILAR SITUATION."**



DAVID AND HIS DAUGHTER GRACE



## HOW CBD AFFECTS THE WHOLE FAMILY

We know that PSP & CBD doesn't just affect the person diagnosed, but the whole family. *PSPA Matters* spoke to David Ingram who is living with CBD, along with his wife Tracey and daughter Grace.

### WIFE, TRACEY

"David and I both had good jobs. Life was good and filled with laughter ever since our first date 18 years ago. Since then we married and had our daughter Grace. David also has a son from his previous marriage and I have a son and daughter.

"One morning David noticed that he couldn't shave half of his face. I also noticed that conversations with David were starting to become really drawn out. The doctor suspected a possible brain tumour and David was rushed into hospital for a scan.

"Hearing the news that David didn't have a brain tumour was a huge relief. However, we were told his brain was shrinking. After a number of cognitive tests, and two years after the initial symptoms, we received a diagnosis of CBD in 2017.

"The diagnosis was not explained at all. CBD seemed like the least scary option. It wasn't until I started Googling did I realise what lay ahead of us.

"David's personality has changed. He was bubbly and outgoing, always cracking jokes, but now he's very quiet and just listens. He no longer makes conversation with people because he struggles to find the words. I help get David washed and dressed in the morning. His eating is okay but I make sure to cut up his food for him. He's a bit wobbly on his legs but we aim to go out every day to keep them moving.

"I don't really think about how I'm now having to take on more of a caring role for David. It's just something you do. I want to be there for him and help him in any way I can. More than anything we all simply feel totally heartbroken at what is happening to David.

“David can no longer drive and had to leave the job he loved. Slowly, one by one, things are being taken from him. I’ve also finished work. David had a fall at home and I decided then and there I needed to be with him. I didn’t want to wait for him to get really poorly, instead I wanted us to make the most of our time together.

“With both of us being so young leaving work was incredibly stressful. We were both worried about finances. After David left work I contacted PSPA for support. PSPA sent someone round from the Department of Work and Pensions who advised us on what we were entitled to and completed a PIP assessment. We knew nothing about what we were entitled to, so this made our lives so much easier. My aim is to help David to continue to do what he has always enjoyed.

“Every day we aim to get over what new challenge awaits us. It’s hard though to keep life as normal as possible. You find once diagnosed with something like this, people tend to drift away. At first everyone says they are there if we need anything, but then you notice the invites become more sparse and less people call in. Despite all this we have a lot of fun together and try to find humour in most things. It helps to defuse the stress. We don’t look too far into the future.”

#### **DAVID, LIVING WITH CBD**

“With Tracey’s help I am trying to keep doing the things I’ve always done, but there’s no hiding from the fact that I’m getting worse. Even when we go to the bookies to place a bet, I can no longer fill the coupon in myself and need Tracey to do it.

“I don’t see that many friends now. Mostly I’ll see them in passing, when we are out in town. I do get deserted and I know we are no longer invited to things. But at the same time, I don’t want to go anywhere where people feel sorry for me.

“The worse thing is I like to make people happy, so now I feel so sad I can’t do that anymore. I feel sad for Tracey and Grace and what this is doing to them. We do still have a laugh though and I’m grateful for that. I just wish it wasn’t me, but then I wouldn’t wish this on anyone else either.

“But, I can still enjoy music and we do have good times. I’m very proud of Grace, as well as our other children. Tracey couldn’t look after me better and I love her very much. She’s brilliant, I don’t know where I would be without her. It’s a comfort to know they are there with me.”

#### **DAUGHTER, GRACE**

“I’d hear CBD mentioned in the background at home when mum was talking to someone. Mum gave me a book to read about CBD, but I didn’t really understand. Now I see how it has affected Dad I understand a lot more. I think I just needed to see it rather than read about it.

“Dad was always making jokes. Gradually we noticed when he was making jokes they’d take much longer and they started to become boring to listen to. That was the main thing I noticed, but now, I’m starting to forget what he was like before he got ill.

“Last year it dawned on me that Dad wouldn’t get better. His talking is getting worse and his legs are wobbly and not very stable. It takes him ages to get out and you have to simplify things for him. Sometimes I help him to get on the stair lift and I tell him what colour to press for up and down. It’s just the simple things I can help with, Mum does the rest.

“Occasionally I’ll talk to my close friends about what is happening to Dad. It depends on my mood. There are other times I don’t want to talk about it at all. When I go to school I feel like I get a break from the situation at home, but then I find I tend to focus on stressing about school. I don’t feel angry about our situation, but I do feel upset. But it is just the way it is now.”



**DAVID AND TRACEY**



ANGUS LEE AT HIS CHARITY GOLF DAY FOR PSPA



## MOVED TO TAKE ACTION

The vast majority of our fundraisers have a personal reason for supporting PSPA. That personal reason is often a family member, friend or colleague who is living with PSP or CBD. Fundraising for many is a way to focus on something positive.

### FUNDRAISING FOR FAMILY

After watching her husband, Brian Suckling, die from PSP, Denise, along with her two sons, are determined to continue to raise money to support PSPA. Denise said: "Brian was such a strong man, but at the end, it wasn't really him. Throughout it all though, he never complained. I'm so grateful we had the years we did, but it is hard to live without him."

"After such a horrible experience, raising money for PSPA seemed a natural thing to do. We live in a village and held a coffee morning for PSPA. My son's and I have sent in donations, and one of my sons is doing some fundraising at work. It is comforting to think that we can possibly help others going through what we did."

Hayley Alderson's dad died of PSP. Hayley decided to take part in our 5KYourWay challenge to raise awareness and funds. Hayley said: "Watching my dad, Marcel live and struggle for seven years with PSP I needed to do something. My family and I have seen first-hand how little understood PSP is and how damaging that can be. As a family we'd sold raffle tickets and shared PSPA's information with others to raise awareness, but 5KYourWay was the first fundraising event I took part in."

"The 5K challenge looked a great way to get kids involved in an important cause, one deeply personal to us, but at the same time wasn't too demanding. My kids are very aware of the condition Dad had. As a family we often talked about PSP. By the end, Dad



wasn't able to walk or speak so they saw how PSP was affecting him.

"My son Isaac, 6 and daughter Isla, 4 were excited to do the 5K. I think it is important for children to get involved with fundraising. It helps them do (and enjoy) something positive in what was a devastating situation. It also teaches them that not everyone is well and healthy and that we should always help others when we can."

### FUNDRAISING FOR A COLLEAGUE

When keen golfer Angus Lee heard about a colleague's husband's diagnosis of PSP he knew he wanted to do something to help. Combining his love of golf with an opportunity to raise money seemed like the perfect way to make a difference.

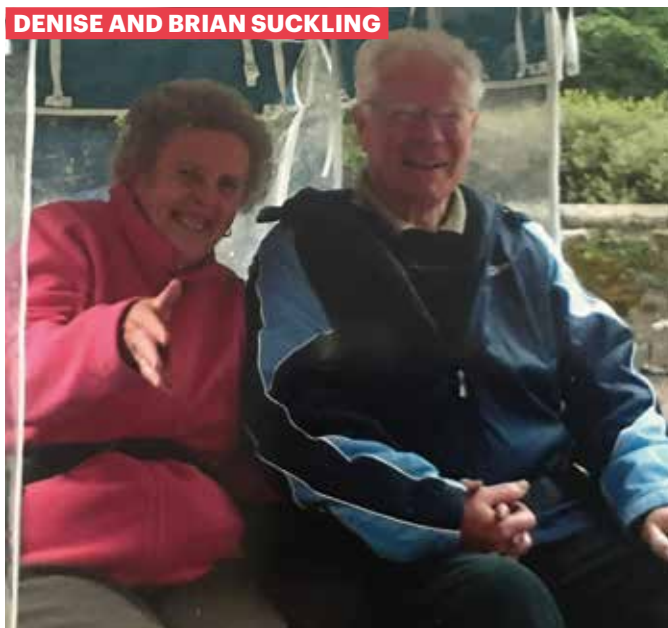
"I've always donated to charity, but never actually organised a fundraising event. It was only when I was talking to a colleague, Isabel Pirie, about her husband Richard's diagnosis of PSP I decided to do something. Richard was progressively getting worse and needed 24/7 care.

"I'd never heard of PSP. I remember saying to Isabel that I presume the government are funding research into finding treatments. I was surprised when she told me there weren't and that PSP received very little funding. Hearing that all the funding going into PSP was voluntary sparked me into action. I thought that helping the charity raise money is something I could do to help. I have a lot of contacts and was confident I could organise a golf day that would raise a good amount of money for PSPA.

"I just feel that I'm a lucky person. I'm in good health and I know some people are not so fortunate as me. I think those of us who are fortunate are in a good position to help others. It doesn't cost me anything but time."

**"HEARING THAT ALL THE FUNDING GOING INTO PSP WAS VOLUNTARY SPARKED ME INTO ACTION."**

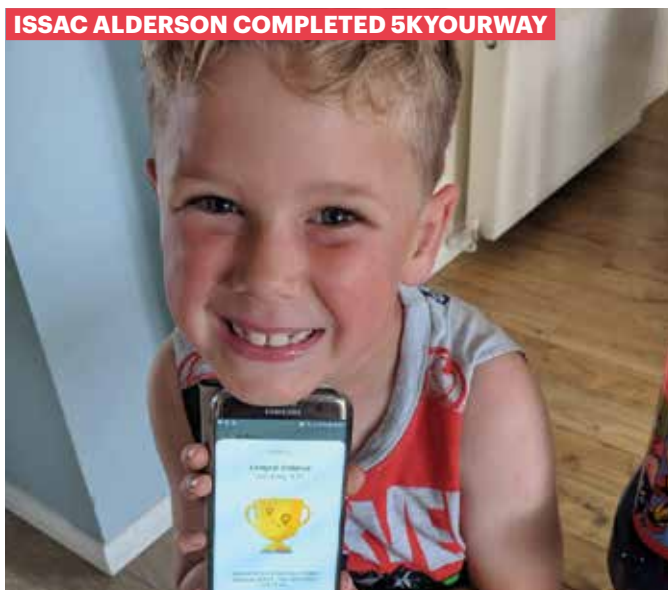
**DENISE AND BRIAN SUCKLING**



**ISLA ALDERSON COMPLETED 5KYOURWAY**



**ISSAC ALDERSON COMPLETED 5KYOURWAY**



SEB COPE AND JANET HARDWILL



### FUNDRAISING FOR A FRIEND

Seb Cope recently completed the London to Brighton bike ride on a penny farthing in tribute to his friend Janet Hardwill.

Seb said: "When I worked for Janet's husband Peter, I'd regularly see her in the office. She's a lovely lady, always very sociable and active in the community. Since being diagnosed with PSP I've seen how the condition has affected her, particularly her mobility and speech.

"Like most I'd never heard of PSP until Janet was diagnosed. Around a year ago Janet talked to me about doing a 5K bike ride for PSPA. I've always been a keen cyclist so doing 5K didn't seem enough of a challenge.

I saw the London to Brighton bike ride and thought that would be perfect. To make it even more painful I decided to do the challenge on a penny farthing. Completing the 55 miles from London to Brighton with no brakes and a 48-inch wheel was certainly a challenge. I felt every single bump on the road!

"It's a scary thing to ride the penny farthing for so many miles, but it's nothing compared to the frightening reality of living with PSP every day. Having worked for Janet's husband Peter, for more than 15 years means Janet is like family to me and the least I can do is draw attention to PSP. When I first told Janet I think she was probably a bit shocked, but for me it's a way to show how much I think of her."

---

**"IT'S A SCARY THING TO RIDE THE PENNY FARTHING FOR SO MANY MILES, BUT IT'S NOTHING COMPARED TO THE FRIGHTENING REALITY OF LIVING WITH PSP EVERY DAY."**



**When Karen Mitchell's father, David Garfield Davies, Lord Davies of Coity CBE received his diagnosis of PSP, the family decided they needed to do something positive. Lord Davies was former general secretary of Usdaw, one of Britain's largest trade unions. Karen shares why it is so important to the family to continue to support PSPA, even after her father's death.**

Karen said: "Dad received his diagnosis of PSP in September 2017, after four years of misdiagnosis and not knowing what was wrong. Straight away the whole family wanted to do something to support the charity. We decided to hold a coffee event in my parents' house, followed by a 10k run the next day. Over 50 of us did it – it really brought everyone together and we raised a great amount for PSPA."

"Faced with such a horrible diagnosis we needed to stay busy. It helped us cope. We received no information or advice from doctors, and soon realised no one knew much about the condition. This lack of knowledge and awareness drives us to do whatever we can to help change the situation. We don't want anyone else to go through what we did."

Dad was involved with Usdaw for many years so during the Annual Delegate Meeting they dedicated a night to him where all the proceeds went to PSPA in honour of Dad. We were struck by how generous everyone was. The place was packed. We handed out leaflets and passed a proposition to government to raise awareness of PSP."

"If Dad could see all this he'd be really proud. Unfortunately his condition deteriorated rapidly, so by the time he was diagnosed I don't think he could comprehend what was wrong with him. Even though Dad has now died we plan to continue to do what we can to support PSPA. We get so much comfort from doing something positive so that others don't have to go through what we went through. Dad spent his career helping others. I can't think of a better thing to do now in his memory than to do the same for people living with PSP."

If you would like more information or ideas on how you could fundraise please visit our website [pspassociation.org.uk](https://pspassociation.org.uk) or email [fundraising@pspassociation.org.uk](mailto:fundraising@pspassociation.org.uk)







At our 2018 Study Day at The Royal College of Physicians, we launched the first ever Professionals' Guide to Corticobasal Degeneration. Since then we have sent out over 800 copies to health professionals across the UK. We have also reviewed our Pathway of Care for PSP and are about to launch our new Professionals' Guide to Progressive Supranuclear Palsy.



To complement these two publications, we have developed a new online interactive resource that will be launched at the end of October. This resource is the first of its kind for PSP & CBD and provides evidence-based information on symptom management and best practice. There is an opportunity for health professionals to download information and build a care plan for people they are supporting. This resource will provide health and social care professionals directly caring for people with PSP & CBD with all the information they need to provide the best possible standard of care.

We know that lack of knowledge and awareness of PSP & CBD can hamper health professionals' ability to provide good care. Alongside this, issues around care coordination can also mean families are having to deal with a large number of professionals who may be unfamiliar with the issues faced by living with these progressive conditions. Problems often arise

when people are admitted to hospital following a fall and staff are not familiar with PSP or CBD. With this in mind, to complement this resource, we have developed a medical alert card for people to carry with them at all times. The card provides information on the common symptoms of PSP & CBD and also links to the interactive resource enabling health professionals to access information at the touch of a button.

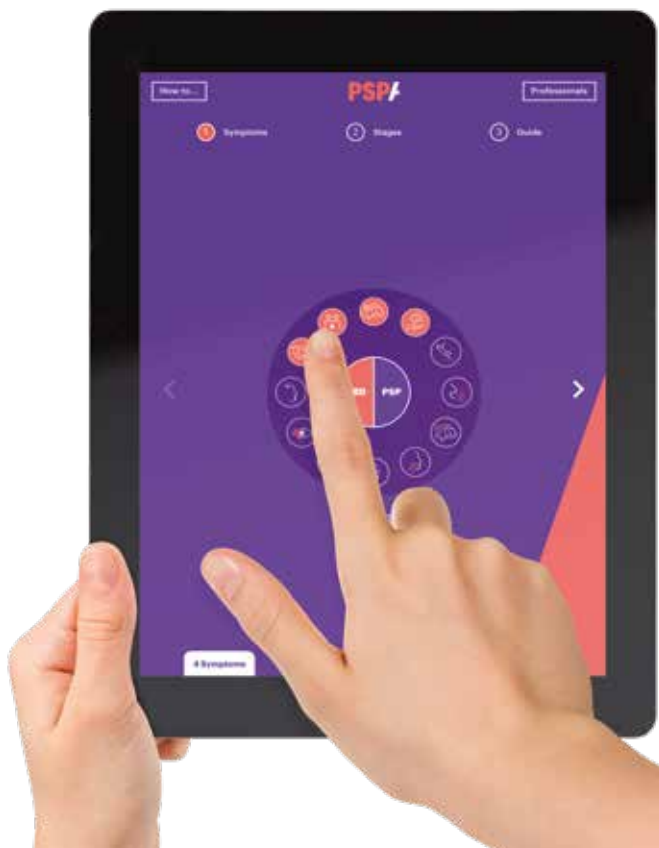


**Professor David Oliver,  
Consultant Physician in  
Palliative Care**

"This interactive resource will be very helpful for all professionals looking after people with CBD & PSP.

Information is readily available to help them improve the care of people with CBD & PSP, so that the quality of life of the patient and their family can be maintained to the best level possible."

**If you are a health and social care professional and would like to be updated on the launch of our new online resource please contact our helpline on **0300 0110 122** or email [helpline@pspassociation.org](mailto:helpline@pspassociation.org)**



## ALERT CARDS

With the launch of the interactive resource we are pleased to be able to offer our new Alert Card to those of you living with PSP & CBD. The card explains that you have PSP or CBD and the main symptoms you may be experiencing. The laminated card fits into a wallet or purse ready to be shown discreetly if you need assistance in a public place, or if you are having problems communicating. The card also provides a link to our new interactive resource so if you need a health professional to know about PSP or CBD at the touch of a button you can offer them the card. To order your PSP/CBD Alert Card please contact the Helpline on **0300 0110 122** or [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

**Special thanks to CBD Solutions for funding the Professionals' Guide to CBD and the online, interactive resource.**

GWEN AND MICHAEL LEAVER



## “MY DAYS REVOLVED AROUND CARING FOR GWEN”

**Michael Leaver’s wife Gwen was diagnosed with PSP in August 2013. Michael shares why, even after Gwen’s death, he still wants to be involved with PSPA.**

Michael said: “Gwen and I had 43 happy years together and I had the pleasure in helping to raise her three wonderful children. Life was good. I’d retired at 70 and was enjoying spending time with my family. After retirement Gwen and I fell into a pleasant routine of playing bridge, meals out, enjoying the theatre and taking holidays. Nothing was out of the ordinary until I started to see issues with her walking so we went to the GP.

“Our GP was well informed and said it could possibly be PSP and that he would refer us to a neurologist. Gwen underwent tests and scans and three days later was given a diagnosis of PSP. The neurologist spelt out the facts. The fact most alarming to hear was that it was incurable.

“We got home anxious to learn as much as we possibly could about PSP. We contacted PSPA and started going to the local groups. When the Redbourn group was formed we joined that. In total we attended six different groups. Meeting people living with the condition was incredibly useful for both of us.

“Most of the help we received came from PSPA. They prompted us to get in touch with various organisations locally and throughout Gwen’s illness we were well served with equipment and medical support. It was through the PSPA that I found out about the personal allowances to which we were entitled.

“Gwen was very stoical throughout her progression with PSP. She never broke down or cried about her situation. She just accepted it and as each phase came along she never complained about her lot, even though she was more than entitled to.

“Gwen stayed at home until the end. That end all happened quite unexpectedly in September last year. Gwen was taken to Hillingdon Hospital and was diagnosed with a bladder infection. I anticipated she would be home within a week but her condition deteriorated and she died eight weeks later. I cannot speak highly enough about the service and care we received from the NHS. At all times they did their best to manage Gwen’s condition and kept myself and the ‘children’, (no longer children being in their



## FAMILY AND FRIENDS DAY



50's), as well informed. The hospital staff couldn't have been more caring and thoughtful.

"During the time Gwen was in hospital it was the Day of Atonement (Yom Kippur). It is tradition in our synagogue that we raise money for charity on that day. The money raised is divided into three between a Jewish charity, an Israeli-based charity and a charity supporting the community as a whole. Last year I was successful in asking that PSPA be the 'community' charity and personally made the five minute appeal. It struck quite a chord with members and over £5,000 was donated to PSPA.

"After Gwen died, it was very hard because my days revolved around caring for her. It was hard to know what to do with myself. Throughout this time our three children provided me with so much support. Eventually I had a word with myself and thought I have to start living. I realised where I live in the Northwood area there must be a need for a regular lunch group for widowers. I decided to set one up and targeted local churches and my own synagogue to get the word out. We now have 12 - 15 widowers who meet for lunch every second Tuesday.

"Everyone's situation of PSP will be different. However, the one thing I would advise is to make sure you are accessing all the help that is out there. At the beginning I didn't realise so much help was available. We had professionals out to our flat to assess what equipment Gwen needed and we had a speech and

language therapist helping Gwen manage her speech problems. All this helped Gwen manage the symptoms of PSP.

"While I was Gwen's main carer we received support from paid carers who would visit a set number of hours every month. This helped me leave the flat for meetings, knowing that Gwen was in safe hands. Other than that I was with Gwen more or less all the time. However, I never saw it as a problem and accepted it as part and parcel of getting old.

"Gwen was determined to do whatever she could to help research into PSP. She participated in the Oxford research programme and donated her brain to the Brain Bank. Now, even though Gwen is no longer here I want to continue to be involved with PSPA. I still attend the meetings in Redbourn and the Family and Friends day. The charity did splendid work for Gwen and if there is some minor way I can repay that I'd be delighted to do it."

---

**"GWEN WAS DETERMINED TO DO WHATEVER SHE COULD TO HELP RESEARCH INTO PSP."**

# 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 Community Outreach Volunteer or 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 Monday, Wednesday & Friday 7pm-9pm.**

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

# PSP/

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

T 01327 322410  
[info@pspassociation.org.uk](mailto:info@pspassociation.org.uk)  
[www.pspassociation.org.uk](http://www.pspassociation.org.uk)

Registered charity number England and Wales 1037087 and Scotland SCO41199.

