

# PSP/MATTERS

AUTUMN 2020



**NEW RESEARCH  
STRATEGY SETS  
OUT OUR ROLE  
IN PSP & CBD  
RESEARCH**

## **ALSO INSIDE**

- Edoardo de Natale talks about new neuroimaging study in PSP
- Read how our volunteers responded to COVID-19

# 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

Life has changed beyond all recognition. My thoughts are with everyone living with PSP or CBD during these challenging times. I know for many, lockdown has deprived them of vital sources of support.

As soon as the coronavirus pandemic hit we set about putting

plans in place to support people with PSP & CBD. We created a new volunteer companion role, updated information on our website and held regular Ask the Expert sessions online.

When the office doors closed in March, our helpline staff and volunteers acted swiftly to ensure our services remained in place. What's more, many past and new volunteers contacted PSPA to offer their services. And many of our amazing fundraisers quickly adapted to our new reality by swapping their challenges to virtual ones.

I'd like to thank all of you for your efforts both during this time and in the coming months. It certainly has demonstrated the strength of the PSP & CBD community.

I want to reassure you that our work continues. Of course we face significant challenges. Like most charities, we anticipate a drop in income due to the cancellation of events such as the London Marathon, but we are determined to find new ways to support those living with both conditions.

Thanks to your support we recently launched a new Support Grant service for people with PSP & CBD (page 26) and hope this will help enhance people's quality of life. We've also developed a new research strategy based on priorities outlined by those living with PSP & CBD.

The situation is challenging, but our resolve to invest in PSP & CBD research and to develop our services further remains as strong as ever (page 12).

As always, thank you for your continued support.

**Andrew Symons**, Chief Executive

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## USEFUL CONTACTS

Main contact **01327 322410**

**info@pspassociation.org.uk**

Helpline **0300 0110 122**

**helpline@pspassociation.org.uk**

Fundraising **01327 322414**

**fundraising@pspassociation.org.uk**

Volunteering **01327 356137**

**volunteering@pspassociation.org.uk**

Andrew Symons, Chief Executive

**01327 322413**

**andrew.symons@pspassociation.org.uk**

Carol Amirghiasvand, Director of Engagement,

**01327 356137 carol.amirghiasvand@**

**pspassociation.org.uk**



ALEX THOMPSON

### JACKPOT WINNER DONATES BACK PRIZE TO PSPA

PSPA supporter Alex Thompson won the first prize of £500 in our Summer Raffle. As soon as he heard about his win Alex wasted no time in donating his prize to PSPA. Alex said: "This is the first time I've ever won a cash prize as large as £500. I've decided to donate the winnings to PSPA. The charity is doing a sterling job and the funds will help them meet their goals. I'll continue to support PSPA and make the world aware of this illness." We are incredibly grateful to Alex for his generous support.

### PSP & CBD AWARENESS WEEK

A film premier, a moving poem, Red Flags and an Ask The Experts session – our PSP & CBD awareness week had it all! The week's activities was a huge success reaching over 70,000 people on Facebook and almost 18,000 on Twitter.

Awareness activities kicked off with a Facebook screening of Freya Hannan-Mills's film, Swallow. The film was based on her experiences of living with and caring for her Nana, Margaret who had PSP. During the film people also had the opportunity to ask Freya questions. It proved so popular that we had to put on a second viewing.

Freya said: "I feel incredibly lucky that it is a story that has resonated with people. I try to tell everyone I can about PSP as I understand how important it is to bring greater understanding of the illness. My thoughts are with everyone who is currently dealing with it. I think you are all warriors."

You can read some of the questions people asked Freya on our website [pspassociation.org.uk/swallow-film-qa/](https://pspassociation.org.uk/swallow-film-qa/) and catch up on our Ask The Experts session by visiting [pspassociation.org.uk/information-and-support/zoom-qa-sessions/](https://pspassociation.org.uk/information-and-support/zoom-qa-sessions/)



SWALLOW





### OUR RESPONSE TO COVID-19

The global pandemic has greatly challenged our usual means of support. We know for many, our Local Groups provide vital support and friendship to those affected by PSP & CBD. The cancellation of all group meetings was a huge disappointment to us all.

In response to the threat of COVID-19 we've developed new ways of working, created a new volunteer role (page 8), and improved our use of technology to help plug the gap in support to people living with PSP & CBD. Our amazing volunteers have played a huge part in this and, since March, rapidly devised new ways to provide local support remotely with regular phone calls, emails, newsletters and WhatsApp messages.

With lockdown removing the option of meeting in person, Zoom became the way for us all to keep in touch. Our Zoom meetings (to help replace Local Group meetings) quickly became a success and we are now expanding our offer to cover the whole of the UK.

A huge benefit of our new online Zoom meetings was that it enabled us to provide meetings in areas of the UK where we didn't have any local groups. Our first South

West Peninsula Group meeting took place in August with people attending from Cornwall, Devon, Dorset and Wiltshire. It proved such a success they are now meeting once a month. Plans are under way to offer meetings in Northern Ireland, Cambridge and Essex.

We know there is nothing quite like meeting friends you've made at our Local Groups in person, but sadly this is something we are not going to be able to provide for some time. However our new Zoom meetings do offer an opportunity to speak to each other and, of course, have some fun.

If you would like to attend please email [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk) to find out when the next one is happening in your area.

### Q&A SESSIONS

Our new Q&A sessions for people affected by PSP & CBD are designed to provide the opportunity to (remotely) ask our helpline and health professionals questions. Questions are sent in prior to the meeting to save time. Our first session, 'Ask the Helpline', was held in June with 26 people. We covered a variety of topics including issues with swallowing, care provision, vision and symptom management.

Our following session, 'Ask the Experts' took place during PSP & CBD Awareness Week in July, when we were joined by neurologist Dr Boyd Ghosh and Jade Donnelly, APS Coordinator and Specialist Physiotherapist. Those attending asked questions on a wide range of areas including problems with speech, vision, cognition and medication. Feedback following both sessions have been very positive so we are planning to hold more Q&A sessions over the coming months.



### BREAKING NEWS

Following a five year term as Chair of Trustees, Simon Koe, recently announced he will be stepping down. During his term, Simon helped PSPA increase the support it provides to people affected by PSP & CBD and driven our largest ever research investment with the funding of the PROSPECT study.

We will all greatly miss Simon and would like to thank him for his dedication to people with PSP & CBD. In the next edition of *PSPA Matters*, we will share more about Simon's huge contribution to PSPA.

The Board of Trustees are conducting a selection process for the next Chair of PSPA and will announce an appointment shortly.

**If you would like to support our work. There are many ways you can make a donation to PSPA.**

- Phone – call 01327 322414
- Text – text **TEAMPSPA** to **70085** to donate **£5**
- Set up a regular gift online [pspassociation.org.uk/donate](https://pspassociation.org.uk/donate) Every penny you give will make a difference to people with PSP & CBD, their carers and family. Your donation will fund our information and support services and will be invested in research into PSP & CBD.





## NEW IMAGING TECHNIQUES TO AID DISCOVERY INTO PSP

Edoardo de Natale is a neurologist and a senior clinical research fellow at the Neurodegeneration Imaging Group, based at the University of Exeter and directed by Prof Marios Politis. Edoardo talks to *PSPA Matters* about state-of-the-art molecular imaging techniques and the potential they have for providing a greater understanding of PSP.

Edoardo said: “We specialise in neuroimaging, which is the use of various techniques to view the structure and function of the brain. We use magnetic resonance imaging (MRI) and positron emission tomography (PET) to provide structural and functional information about what is happening in the brain. PET is a relatively new technique which uses radioactive substances called tracers. The radioactivity makes it possible to measure how much of the tracer connects to different parts of the brain.

“In people with PSP, many vital nerve cells (neurons) of the brain die, but we currently don’t know why. We do know however, a protein called phosphorylated tau accumulates in the brains of people with PSP. This protein is toxic and is believed to play a key role in the development of symptoms. It’s also thought that the regions of the brain where this protein builds up affects the type of symptoms that develop.

“With PET we are aiming to understand more on a molecular and cellular level. By using PET we will not only be able to better understand alterations made to cells, but also alterations to how the cells use small substances called neurotransmitters, such as Dopamine, or Serotonin, to communicate with one another. With PET imaging, we can understand exactly

which substance is lacking and where, significantly improving our knowledge of the mechanisms of disease. We can also see when, how much and where certain proteins such as phosphorylated tau and amyloid clump in the brain, thus giving us precious information also about this process.

“Our studies aim to provide the scientific community with a greater understanding of disease. This will help us track the progression of PSP, and importantly, help with the discovery of new targets for the development of effective treatments aiming to halt or delay the progression of symptoms.

“MRI is a different type of scan, which gives detailed pictures of the brain and does not involve any radiation. In this study we will be using MRI to provide detailed information about brain structure and function, as well as to complement PET analysis.

“This area of neuroimaging has exploded in the last decade and there are many studies using this new technology. Indeed amyloid imaging using PET is now approved for clinical use in the diagnosis of Alzheimer’s disease. We hope that it will do the same for imaging tau in people with PSP. Research published so far has indicated tau is a promising target for therapy. So, if

we can replicate the success of PET in tracing amyloid, we could potentially achieve much earlier and far more accurate diagnosis in people with PSP.

“Information gained from this study will also greatly aid clinical trials. Clinical trials offer the most hope for people living with this condition today. Sadly no really effective drug for PSP exists as yet. One possible reason is that we try to treat the disease when the damage has been already substantial. In Alzheimer’s disease we have identified a stage that is a sort of ‘gateway’ to the disease and is a potential useful window to treat the disease as early as possible. Another reason is that we are not sure yet on what molecule, process, or cell to target to treat PSP. Fortunately, there is something coming up that has potential.

“Clinical trials in PSP with very promising potential drugs are blooming around the world. Tau is the target for a number of compounds that are currently at an early stage of development. At the University of Exeter, for example, we are at the very early stages of starting a large multicentre clinical trial in patients with PSP. The trial seeks to test a drug therapy targeting tau. The results would hopefully provide long awaited solutions to patients with PSP, although they will be some time away.

“I appreciate the struggle of patients awaiting good news from research on PSP. Unfortunately, the development of a safe and effective compound is a struggling and lengthy process. Generally, any drug undergoes a three-step process to be deemed safe and effective against a disorder. The steps are called phases (phase one, phase two and phase three).

“The phase one serves to understand whether a potential compound is safe. Researchers design a study on a small number of healthy people who will receive a dose of the compound to see if it gives side effects. If it is safe, the compound moves onto phase two. This stage is conducted on a larger number of healthy people and patients. This serves to understand more about the physiological effects of the drug in patients, as well as to gather further data about its safety.

“Finally, the drug moves onto phase three trial which is when we test the drug on a very large number of patients (hundreds, or thousands) with the condition to see if the drug is effective. These studies usually test the drug against a placebo, if an effective therapy is not available, or against the best clinical treatment, if an effective therapy is available. Researchers will need to see a marked difference between the placebo and the investigational compound to conclude that the drug is effective. This process ensures that every compound that enters the market is safe and effective. However, it is very lengthy. There are currently many clinical trials taking place around the world into modifying therapies for PSP.

“Many millions have been invested so far in research for neurodegenerative diseases. Rarer diseases, such as PSP, are sometimes overshadowed in attention and funding by more common diseases, such as Parkinson’s disease and Alzheimer’s disease. But we can learn some lessons from this research as well. Some of the symptomatic drugs currently used to tackle symptoms of PSP are ‘borrowed’ from Parkinson’s disease. From Alzheimer’s disease, a disease characterized by a severe build up of tau, we have learned that the degree of tau deposition is correlated with the disease severity. We have concluded that tau can potentially be a good target for the development of a therapeutic compound not only in Alzheimer’s but also in PSP.

“Despite the challenges research is progressing. If you look back ten years there was much less understanding of the clinical science of PSP. The management of patients has improved and we have evidence of the importance of coordinated multi-disciplinary care. I firmly believe five years on there will be more options to enable patients to live as well as possible with PSP.

“The role of charities like PSPA is very important in helping to push forward improvements in the care of people with PSP. I’m looking forward to working in closer collaboration with PSPA and work with them on designing studies that patients want us to focus on.”

**“IF YOU LOOK BACK TEN YEARS THERE WAS MUCH LESS UNDERSTANDING OF THE CLINICAL SCIENCE OF PSP.”**



## PANDEMIC SPARKS VOLUNTEER RESPONSE

For many people living with PSP & CBD, lockdown deprived them of their usual sources of support. PSPA Local Group meetings were postponed, day services were cancelled and respite put on hold. For some, lockdown resulted in feelings of isolation and loneliness. For others, they simply missed having someone outside of the family to talk to and share experiences with.





**“NO CARERS,  
NO RESPITE  
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BEEN EASY.”**

While the global pandemic has greatly challenged traditional means of support, what has emerged is the strength of our PSP & CBD community. Once news of the lockdown was announced, many people with past experience of PSP & CBD contacted PSPA to offer their help and support. They have all lived with PSP & CBD and immediately recognised the impact lockdown would have on families. Thanks to their dedication, we have been able to support people affected by PSP & CBD by creating a volunteer companion service to help overcome some of the social isolation felt by those self-isolating.

One of our helpline's first-ever volunteers, Doreen Walker was prompted to return to volunteering due to the pandemic. Doreen's husband Raymond died from PSP ten years ago, so Doreen contacted PSPA to see how she could help.

Doreen said: “It has been a privilege to talk with my ladies, who all remain cheerful and positive in spite of the difficulties they face. I've enjoyed speaking to them and feel that we've become friends. Sometimes I think it's easier to talk to a stranger than your family.

“Of course, everyone is different and we each have our own unique circumstances, but I know caring for someone with PSP or CBD isn't easy. And sadly, with the current pandemic, it's making an already

challenging situation worse. For my part, I am keen to help do whatever I can to help in any way possible.”

During lockdown Doreen called Pamela Wright. Pamela's husband George was diagnosed with PSP a year ago. With the threat of COVID-19 becoming ever more frightening, Pamela stopped daily carer visits and managed George's needs alone. Pamela talks about her experience during lockdown and how she has come to see Doreen as a valued friend.



**DOREEN WALKER**

Pamela said: "George used to go to the hospice every Tuesday. It was nice for him and it also gave me a chance to take some time for myself. When lockdown happened that stopped. I couldn't leave George home alone, so since March we haven't left the house.

"I was frightened because George is vulnerable, so we stopped the carers' visits. While I greatly missed the carers, I felt much safer not having anyone in the house to reduce his chance of infection. No carers, no respite support and limited access to people outside of the home hasn't been easy. COVID-19 has certainly made an already difficult situation worse. Caring for someone with PSP is demanding. Thanks to our wonderful neighbours we were never short of what we needed.

"I've come to greatly appreciate my calls from Doreen. We don't just talk about PSP, but chat about cooking, helping our neighbours and the family. I've come to really enjoy our chats, she is a lovely, pleasant lady and I know she would gladly do anything to help. With Doreen, I feel like I'm talking to a friend. It has been immensely helpful to talk with someone outside of the house."

Liam Trainor's dad had PSP before he died in 2018. Liam saw on Instagram our appeal for COVID-19 volunteers.

Liam said: "I've seen how distressing and isolating this condition can be, together with the problems around diagnosis and a lack of awareness. In the midst of a global pandemic, with people prevented from accessing outside support, feelings of loneliness must be considerably worse.

"Watching the courage of my dad living PSP, and the incredible way my mum cared for him, made me want to provide companionship to those locked down and living with challenges of PSP & CBD. It's uncommon (even among healthcare professionals) to come across people who've heard of them. By becoming a companion volunteer, I hoped to help people currently impacted by the condition, in whatever small way I could, by drawing upon my own experiences and providing some external interaction in these unenviable times.

"Life for people with PSP & CBD and their carers can often be inexplicably demanding, and both parties should know that they are amazing and that people care about them, even strangers. So I phoned Hazel, whose husband has PSP, and asked if she wanted me to call occasionally.

"Lockdown has reduced our social networks and taken away our ability to meet friends and family.

**LIAM TRAINOR**

## **“THE COMPANIONSHIP CALLS HAVE REINFORCED HOW MUCH I MISS HAVING DAD IN MY LIFE, BUT I TAKE GREAT COMFORT IN KNOWING THAT HE WAS SO WELL CARED FOR. I ENJOY VOLUNTEERING IN HIS MEMORY.”**

Speaking to Hazel has been a privilege and very rewarding. Hazel speaks with great clarity and is so dignified in dealing with the challenges of PSP. She talks about aspects of the disease I can relate to, which make me think back to how life was during Dad's illness, and how bravely my mother and he confronted the condition, showing positivity and resilience I can only aspire to. Through conversations with Hazel, I find myself reflecting on how much my parents went through, and how inspirational they are to me.

“The companionship calls have reinforced how much I miss having Dad in my life, but I take great comfort in knowing that he was so well cared for and I enjoy volunteering in his memory. He would want me to help those facing isolation, a feeling my own family definitely felt ourselves at times. I'm grateful it brings me into contact with remarkable people like Hazel.”

Hazel Robertson's husband Brian has PSP. Like Pamela, Hazel also stopped the daily carer visits and self-isolated. Talking about the support from Liam, Hazel said: “Liam is a very reassuring presence. He is so easy to talk to and is very caring. It's so very helpful to be able to speak to someone who understands PSP and be able to compare notes.

“Lockdown hasn't been easy. Brian had carers in every morning to help shower and dress him. I stopped the carers and took over Brian's morning routine. Initially I was very nervous. Brian is a big man, whereas I'm small. I was worried I wouldn't be able to hold him and that he'd fall. Despite my concerns, and despite being soaked every morning, it's been fine. I'm immensely grateful the weather has been nice so we've been able to sit in the garden.

“Both Brian and I have missed normal social interactions. Despite no longer being able to



**HAZEL AND BRIAN ROBERTSON**

communicate I know he misses his friends calling in, as do I. That's why it's been especially nice to receive Liam's calls. It's nice to have a bit of human interaction. He is a grand chap and very reliable. I really appreciate his calls.”

The global pandemic is sadly far from over. We still require volunteers to help support people affected by PSP & CBD.

If you would like to volunteer please email [volunteering@pspassociation.org.uk](mailto:volunteering@pspassociation.org.uk) or call **01327 356137**





# OUR APPROACH TO RESEARCH

Research has greatly improved how we treat many conditions. Sadly, a lack of funding in the field of PSP & CBD research has meant progress has been slow. People with PSP & CBD still commonly experience misdiagnosis, a lack of joined up care and have few treatment options available to them.

We want to help change this landscape through ensuring we direct our efforts to where it will have the most impact. To do this we are developing a new research strategy focused on ensuring more projects take place and more scientists are attracted to the field of PSP & CBD research.

To help inform our strategy we consulted with patients and carers, researchers and health professionals. We also completed a research priority study where we asked people living with PSP & CBD what research they would like to see undertaken. Following this study five themes were identified as being priority areas for people living with PSP & CBD.

- **Raising awareness**
- **Improving diagnosis**
- **Supporting people**
- **Preventing and identifying the causes**
- **Developing treatments**

## **PSPA RESEARCH STRATEGY**

Our new research strategy outlines how we will develop our research activities over the next five years, to continue to advance our understanding of PSP & CBD and discover how to treat both conditions. Not only will the strategy focus on prevention and treatment, but crucially on supporting research which will help people living with PSP & CBD to receive better care and an enhanced quality of life.

Many of our patients identified a lack of provision in the community and the need for more focused support with exercise, physiotherapy and dietary issues noted as areas where there seemed to be a lack of information. Many patients reported once they left hospital they were left alone and that GP's and community-based healthcare workers did not understand their conditions. The priority research study identified a need for improved awareness of PSP



& CBD to ensure the best care was made available to patients. Our strategy will address these key issues.

In funding research we will have a number of different types of grants available. These grants will be awarded to researchers at hospitals and universities across the UK. We are hoping to be able to offer a range of grants to researchers across the five themes identified. We will also address the need for better community-based research to gather evidence on what is lacking in the community so that we can lobby the health service for improved care pathways in PSP & CBD.

Researchers will be offered a range of funding opportunities, including project grants up to £120,000 to fund a specific piece of research. Researchers will be encouraged to apply for funding that addresses one of the five themes identified in our research priority study. Funding will be based on the relevance to our priority areas, scientific merit and novelty. Researchers will also be encouraged to submit proposals based on new innovative thinking and high-calibre research.

Our research strategy is not just focused on funding projects but also people. By using our funding to attract the best clinicians, and by supporting the careers of researchers, we will help to strengthen PSP & CBD research capacity in the UK. Supporting the development of future specialist experts ensures the progress we are making now will be built on and accelerated in the years to come. This funding will include Clinical Research Fellowships to encourage future leaders in the field and Postgraduate PhD Studentships to enable a junior researcher to specialise in PSP & CBD. Over the past 20 years we have seen the impact our Sara Koe Clinical Fellowship has had on helping to create the next generation of leaders and we will continue to do this.

Of equal importance is our small grant award scheme. These grants are focused on helping to generate new ideas and provide pilot data for larger scale applications, or to facilitate the rapid follow-up of important new findings. They will help to ensure a solid pipeline of work and help identify areas for more in-depth research.

We seek to engage people with PSP & CBD in research and will be supporting research that reflects patient views and priorities. We want to ensure that everyone who wishes to be involved in research has the opportunity to do so. We will work closely

with pharmaceutical patient advocacy teams to encourage patient engagement in clinical trials.

Another key part of our strategy is focused on ensuring that we communicate research findings to our PSP & CBD community as quickly as possible. That new data, ideas and discoveries are shared quickly and effectively to help speed up research progress and foster a culture of collaboration.

We are only able to fund ground-breaking research into PSP & CBD thanks to our supporters. It is directly because of their efforts we are able to improve our knowledge and understanding of these devastating diseases and turn this knowledge into effective treatments.

### RESEARCH PRIORITIES

- Prioritise and support research into prevention and causes; awareness and education; improved diagnosis; drug discovery and targeted treatments; improved interventions.
- Build a strong research community and develop the next generation of PSP & CBD researchers.
- Encourage patient engagement and enable people with PSP & CBD to participate in research.
- Communicate research discoveries to the PSP & CBD community and foster a culture of collaboration with other organisations.
- Maximise the impact of our funding through influencing activities and developing close working relationships with research organisations.

### OUR IMPACT ON RESEARCH SO FAR

Our PROSPECT study has advanced researchers understanding of PSP & CBD. By establishing a data set of patients with PSP & CBD, findings from PROSPECT will help address issues around diagnosis and identify potential biomarkers for the diseases that will predict disease progression and aid future clinical trials.

Alongside funding ground-breaking research we also seek to build a strong research community. Our Sarah Koe Fellowship awards have enabled us to attract the best clinicians and develop their scientific expertise. A number of our fellows have gone on to dedicate their life's work to PSP & CBD and also secured additional funding from other major funders.



## ON THE PATH TO DISCOVERY

Alyssa Costantini is the PROSPECT Study Coordinator at UCL. She is the first point of contact for people living with PSP & CBD and their carers who are taking part in the trial. Alyssa talks about her work on the PROSPECT study and how researchers are responding to the global pandemic to ensure this vital work continues.

"After my Masters in Clinical Neuroscience at King's College London, I started working on a number of Prof Morris' studies at UCL. Those studies first introduced me to PSP & CBD.

My role was focused on patient recruitment, and involved the administration of cognitive and movement assessments. The more I saw patients with PSP & CBD, the more I saw how different it was

## **“ALTHOUGH THE IMPACT OF COVID-19 HAS BEEN CHALLENGING, IT HAS ACTUALLY PRESENTED US WITH THE ABILITY TO TAKE SOME TIME OUT TO REFLECT.”**

to Parkinson's. I was struck by how debilitating both conditions are, and how severe disease progression was compared to Parkinson's.

“In November 2019, I took over the role as PROSPECT Study Coordinator, in which I am responsible for the coordination and management of the study. I oversee the data collection for all 29 study sites, quality check data for future analysis, manage finances and facilitate patient recruitment. I'm also tasked with ensuring our patient participants have a positive experience.

“I'm usually the first point of contact for self-referrals to the study. I assess which study arm is appropriate and what's the best way for them to participate. Depending on staffing, I may attend appointments and help with assessments.

“I've seen how altruistic people with PSP & CBD are. They are really invested in research to help push things forward. This extends to carers and family members too. Many have participated as control subjects and share the same determination to help us understand and learn more about both conditions.

“Naturally COVID-19 has had an impact on our work. However, in response we are being innovative on how we are tackling it. We are working on plans to facilitate safe appointments and we're using remote recruitment for patients not comfortable or able to attend sites. Some of the measures we are introducing to accommodate remote testing are saliva kits (as an alternative to blood tests) and clinical assessments via video link so that a patient may take part from home.

“Previously we shared a space with an outpatient clinic, but now we are looking into acquiring our own

allocated research space where social distancing can take place during patient visits. We are aware that this group is vulnerable and we want to make sure patients are safe.

“Although the impact of COVID-19 has been challenging, it has actually presented us with the ability to take some time out to reflect on the data being collected. We also have more time to perform in-depth quality checks to ensure everything is in place for our return to the lab and office.

“PROSPECT is now in its second phase. We've done some early data collection and seen some interesting insights. We published our baseline paper in JAMA Neurology last December in which we discuss an array of subtypes seen in PSP & CBD. As the clinical features for both diseases are overlapping, identifying distinguishing features of these subtypes will help for early diagnosis and identify patients in the early stages who are eligible for future clinical trials. Another one of our primary aims of the study is to track disease progression as this may vary between patients. By following up our participants over time, we hope to identify biomarkers which will help us to better track the disease course.

“With these degenerative conditions there is no cure, a lack of early diagnosis and a lack of predictors of disease progression. We want to improve early diagnosis and have in place baseline predictors for progression, which will help healthcare professionals better plan their care and will enable patients to plan ahead to reduce complications. We are optimistic that this study will push our knowledge forwards in these areas. This will then, in turn, have a huge impact on future clinical trials. For possible treatments to be successful they will need to be introduced early in the course of the illness. This is another reason why achieving an early diagnosis is so important.

“Without funding research like this simply wouldn't take place. I'm very aware that the funding that comes from PSPA is from the PSP & CBD community, the majority of whom have seen first-hand the devastating nature of both diseases.

“It's exciting to be part one of the largest studies into PSP & CBD, and I am confident that once concluded, this will greatly add to our knowledge of both conditions. Knowledge that will be used to help patients both today and in the future.”



DAVID BACK AND FAMILY



## DETERMINED TO LIVE LIFE TO THE FULLEST

Despite his diagnosis of PSP, David Back was determined to continue to pursue his passion for wildlife and travel. Before he died last year at 59, David travelled to Brazil, Zambia and India. His wife Karen looks back on his experience of PSP and how the family were determined to make the most of the time David had left.



## **“WE’VE ALWAYS LIVED LIFE TO THE FULLEST AND WERE DETERMINED TO CONTINUE TO DO SO.”**

Karen said: “Early on in our PSP journey someone kindly said that as PSP was life-limiting, we should use our time to make memories with our young family. We’ve always lived life to the fullest and were determined to continue to do so.

“After several tests, scans and a long process of elimination David was diagnosed with PSP in 2015. However signs something was wrong went as far back as 2012, when I started to notice personality changes in David. The charismatic man I knew who was always so full of energy and had a great sense of humour was gradually becoming quite intense, less communicative, often distracted and extremely tired.

“David ran an architectural business. As the business was struggling he was under immense pressure. I simply put his personality changes down to this. I suggested we took a sabbatical to Zambia, a place close to our hearts. Whilst we were in Zambia, David had a couple of falls which we put down to the uneven terrain. It wasn’t until he came back from one walking safari saying he couldn’t look up to see the vultures circling above that we wondered if something was wrong.

“More falls followed including a particularly bad one when he bent down to tie his shoe laces and fell heavily on his face, resulting in a broken nose and an overnight stay in hospital. Our GP noted David would not have fallen like that had there not been something wrong. It warranted further investigation and David was referred to a neurologist.

“At first David’s symptoms did not progress quickly with just the odd cough and splutter, slightly slurred speech and unsteadiness on his feet. He started walking with a stick, later progressed to a walker and latterly to a wheelchair.

“The children initially found his illness embarrassing, but as they got older and his illness progressed they quickly adapted. Georgia made him laugh using his walking stick as a prop in her tap dance. Daniel could imitate his new voice, laugh and certain mannerisms to a tee. Meal times were often stressful

as we still ate at the table as a family, despite the possibility of being showered in water or wine! The children would build a barrier of kitchen roll around their plates to avoid any splutters which David always found very amusing.

“Navigating our way through Personal Independence Payment (PIP) and Employment and Support Allowance (ESA) was complicated and time consuming. There was endless communication with HMRC and several appointments with DWP to establish David’s benefit entitlement. We also updated our Wills and put in place Power of Attorney documentation for finances, health and wellbeing.

“David started having regular appointments with speech and language, physio and eye specialists. We attended an informative PSPA Family and Friends Day in Guildford and later on a PSPA Local Support Group was set up on the Isle of Wight. This group provided invaluable support and David enjoyed going. The wonderful families we met remain close to our hearts.

“Despite the challenges of David’s progression with PSP we continued to live life to the full, taking David everywhere with us. In September 2016 we organised a trip to Brazil to see jaguars in the Pantanal, visit the Iguazu Falls and attend the Paralympics in Rio. His enthusiasm for wildlife and his great sense of humour prevailed, but he opted out of socialising with other guests which was uncharacteristic and sad to see.”





"Two months later David travelled to India with his sister and two close friends, visiting David's favourite places including Agra and Ranthambore National Park. The following year we took a family trip to the Kenya coast with my parents. By this time David could not walk unaccompanied and had two alarming falls whilst we were away.

"Having already signed up to take part in the PROSPECT study, David also became a participant in the PASSPORT study, a double-blind placebo drug trial, in April 2018. David and I joined the Queen Square Brain Bank to donate brain tissue for neurological disorder research. In the days before he died, the hospice liaised with Queen Square to make suitable arrangements and the procedure took place on the day he died. I was informed and it is some comfort that his wishes were realised.

"In October 2018, David had a PEG fitted and whilst it was precautionary at that stage, it was still a turning point for us and I did struggle initially. We tried to keep David eating the things he liked, at Christmas even blending his turkey dinner, ensuring he still had ice cream with Tia Maria and the occasional sip of red wine.

"By Christmas it was apparent David was deteriorating more rapidly. His cognition worsened, he lost the dexterity in his hands and he struggled



with his eyesight, which was the most frustrating part for him. In the last year he listened to audio books and the radio, preferring to lie down to do so.

"A riser recliner chair arrived in December, followed by a hospital bed in January 2019. Our family bed was packed away and I slept on a pull-out sofa bed beside him, later taking it in turns with Georgia. Georgia was very hands on with David's care and took great pride in giving him the perfect wet shave. Daniel's role was more physical. Being taller and stronger, he was able to assist David to and from the bedroom. Daniel was also the one to remain calm in difficult situations including some bad falls.

"Daniel, Georgia and I take great comfort we managed to keep David safe and happy at home with us. The generous Disability Grant from the Isle of Wight Council in 2018 enabled us to install an external lift, a smaller internal lift and a fully disabled bathroom which made a huge difference to David's independence.

"In March 2019, David developed a cough and several doctors attended to check for a potential chest infection. This led to conversations about his future care needs and end of life although I had not realised at this point how far advanced his condition was. Two weeks before he died David was admitted to Mountbatten Hospice initially for respite





## **“DANIEL, GEORGIA AND I TAKE GREAT COMFORT WE MANAGED TO KEEP DAVID SAFE AND HAPPY AT HOME WITH US.”**

care. Despite his obvious weakness I was certain he'd recover. When it became clear he would not be coming home Daniel, Georgia and Bentley, our beloved dog, joined me at the hospice where we stayed for the next week, camped out in his room. David's sister also stayed and we all talked to him, played music and stayed with him throughout. He was not able to communicate other than the odd hand squeeze and thumbs up. It was a very sad but precious time and one we treasure. We spoke to him about letting go when the time was right.

“Having not witnessed anyone in their last few days, it was an incredible experience and not one to be feared. While he took his last breaths we each hugged him. Over 200 people attended David's funeral. There were many tears but also a lot of laughter. A few months later we buried some of David's ashes at our local church and as he wished, in October we

scattered his remaining ashes under our favourite acacia tree opposite Mwaleshi Camp in Zambia.

“David achieved much in his life and devoted himself to conservation, raising £130,000 for many conservation projects. A male black rhino calf was named in his honour and the Luangwa Football Initiative he started in 2016 (after diagnosis) continues in Zambia to this day.

“Although he is no longer with us, David is still very much part of our lives. We talk about him often, look at photos and share wonderful memories. David still influences family life and is ever present. I believe that his legacy will live on through Daniel and Georgia and this long challenging PSP journey has shaped their lives positively. Both are interested in conservation and want to continue to fundraise for PSPA and Mountbatten.”



## THE IMPORTANCE OF ORAL HEALTH

As we all know oral health is important for everyone. Good oral health ensures we have fresh breath, keeps our teeth and tongue healthy and prevents dental infections. As PSP & CBD progress, there may be changes which can make maintaining oral health more challenging. Beverley McClung, a Specialist Dentist at the Special Care Dentistry services on the Isle of Man, talks about those challenges and how to overcome them.

### MOBILITY CHALLENGES

As mobility decreases it may be difficult to get to the dentist's surgery or in/out of a dentist's chair. There are some accessible dental surgeries, and, in some areas, home visits can be offered by special care dental services (sometimes called Community Dentist services).

### DIFFICULTIES WITH FINE MOTOR SKILLS

Loss of fine motor skills may make opening the toothpaste or using a toothbrush tricky. In later stages help with brushing is ideal but a person's wishes must be considered. It can be helpful to have a discussion early on about this issue.

### COMMUNICATION DIFFICULTIES

Deterioration of speech can make it challenging to explain a problem, or to communicate a feeling of pain to others. Allow the individual time to explain or try using a picture board. Taking cues from non-verbal responses is very important, for example, changes in behaviours around food and sleep patterns could be due to dental problems.

### DRY MOUTH

Saliva plays an important role in keeping the mouth healthy. It helps break down food particles, helps

'wash' the mouth and protects the mouth from drying out. People with PSP & CBD may find that they are unable to swallow saliva and it builds up in their mouth or starts to dribble out. The quality and consistency of saliva can also change.

Some medications can cause a dry mouth – your doctor or pharmacist can advise on this. Having a dry mouth can lead to an unpleasant taste in the mouth and a coated tongue. This increases the likelihood of dental decay and dryness/cracking of the tongue and lips. It is easier for ulcers to appear with the reduction of saliva as the tissues all stick together. Drinking enough fluid and taking frequent sips of water can help. Lip balms can help moisten the lips and GPs and dentists can prescribe gels or sprays to help with a dry mouth problem.

### SWALLOWING DIFFICULTIES

As PSP & CBD progresses it usually affects a person's ability to swallow. This can put the individual at higher risk of developing aspiration pneumonia. Dental plaque is a reservoir for bacteria and, if not removed by brushing, can potentially dislodge and be inhaled leading to aspiration pneumonia. Maintaining good oral hygiene and avoiding the build-up of plaque is important for people, including



those who wear dentures or use PEG feeding and can minimise the risk of aspiration pneumonia.

One consideration are changes to eating patterns when someone has PSP or CBD. Often a preference is shown for sweet foods, alongside more regular snacking and food enrichment due to difficulty eating larger portions at mealtimes. I'd advise to try and keep sugary snacks to mealtimes, and offer savoury alternatives. If sugary snacks are eaten, rinsing the mouth afterwards and brushing teeth after each meal will help to maintain effective oral health.

## HELPFUL HINTS TO EFFECTIVE ORAL HYGIENE

### BRUSHING

Regular brushing is the most effective measure for the prevention of decay. Teeth should be brushed twice daily. I would suggest choosing a medium bristle toothbrush with a compact head. The recommendation is to change the toothbrush every two – three months. As dexterity reduces it can be helpful to attach the toothbrush to your hand with either a Velcro strap or a piece of wide elastic. For some people the extra weight of an electric toothbrush can be helpful. It's a good idea to speak to your dentist to see if they can offer any way of adapting the toothbrush to enable you to continue to brush your own teeth for as long as possible.

### THE TWO BRUSH TECHNIQUE

When assisting someone with brushing, carers can find the 'two brush technique' helpful. This involves holding the mouth open with one brush while brushing with the other. Three-sided brushes are also available. It can be tricky to brush someone's teeth so do discuss this with your dentist who will be able to suggest tips.

In the later stages of PSP or CBD when teeth cleaning may be more difficult due to unpredicted clenching shut of the mouth, sliding a tooth brush in under the lip and massaging the front teeth may be all that is possible. However it is essential to keep trying to clean all the teeth, brushing at different times of day may help.

### DENTURE CARE

Care of dentures is important. Don't sleep with dentures in as gum tissue needs time to rest and leaving the dentures in can cause some fungal infections. Dentures should be brushed with soap and water and left in a small amount of water overnight.

### TOOTHPASTE

People with PSP or CBD often find it difficult when their swallow is reduced to cope with the amount of foam produced by standard toothpaste. Low foaming toothpastes can be bought over the counter from dental practices. Select one that does not contain sodium lauryl sulphate - this is the foaming agent.

Fluoride can help prevent decay as it strengthens teeth. Fluoride also slows down the rate which bacteria produce acid in the mouth. Use a tooth paste with a high fluoride content, at least 1450 ppm fluoride. Dentists can prescribe a higher strength fluoride toothpaste which can be useful for increased protection of the teeth where someone may have increased risk of tooth decay (such as a dry mouth).

When brushing do not wet the toothbrush – it dilutes the fluoride and creates foam. Spit any excess toothpaste out after brushing and don't rinse with water or use mouthwash as this will remove the protective fluoride from your teeth. Always use a large pea sized amount of toothpaste on the brush and brush for two minutes.

### VISITING THE DENTIST

It's a good idea to visit a dentist soon after diagnosis, so future dental care can be planned. Problems should be treated early on rather than later when the symptoms may make it difficult for a person to tolerate dental procedures.

Make sure your dentist is aware of your diagnosis and any medication you take. Your dentist may want to see you more regularly for check-ups and cleaning. They may also suggest applying a fluoride varnish to your teeth regularly to reduce the risk of decay. As PSP or CBD progress, it may become more difficult to see your regular dentist. It might be helpful to register with your local community dental or special dentistry service. A special care dental team may be able to provide:

- wheelchair accessible surgery and equipment
- home dental visits with portable equipment
- treatment under sedation
- support, advice and treatment tailored to individual circumstances.

Always check with your dentist to find out if they offer home services or disabled access before changing your routine.

For further information or for help in finding a service in your area please contact our helpline on **0300 0110 122** or **helpline@pspassociation.org.uk**



## SUPPORTING YOUNGER PEOPLE AFFECTED BY PSP & CBD

Kathryn Embree was just 16 when her dad, Mike was diagnosed with PSP. Now, five years on Kathryn wants to set up an online community of younger people affected by PSP & CBD.

“Dad was diagnosed with PSP when I was 16. Naturally I had no idea what PSP was. I felt confused and overwhelmed. None of the information was relevant to someone my age, and while I talked to friends about Dad’s diagnosis, they didn’t really understand what it was like.

“Looking back I know I would have benefited from talking to someone my own age in a similar situation. That’s when it dawned on me how useful it would be to have a community of younger people affected by PSP & CBD where we can share experiences, talk and have a support network outside of our own family and friends. I contacted PSPA to discuss the idea and offered to take on the project as a volunteer.

“I want to set up an online group, with scheduled Zoom or Skype calls where we can meet like regular support groups. We can share experiences, resources and informative films. I really hope that once a parent or grandparent is diagnosed, their children or grandchildren are automatically directed to this new group. I want it to be as inclusive

and flexible as possible, where people can be as involved as they wish.

“To get this going we really need parents and grandparents to direct their younger family members to this group. I know if I had been told about such a group five years ago it would have made a big difference to me. I’m confident this group has the potential to help people, but we need to make sure they are aware of it. I’m excited to see where this project goes and to meet other young people in the same situation as myself.

### DO YOU KNOW A YOUNG PERSON AFFECTED BY PSP & CBD?

Please contact Volunteering on **01327 356137** or **volunteering@pspassociation.org.uk** with their name, email and mobile number if they have one. The group is open to anyone between the ages of eight - 30.



## **“THIS DISEASE TAKES AWAY SO MUCH, I REFUSE TO LET IT TAKE MY VOICE.”**

When a speech and language therapist told Lisa Rodriguez, 49 that her throat muscles were starting to weaken, she decided to bank her voice. Lisa talks about the experience and how it has helped her to retain some of her identity.

Lisa said: “When I was told CBD may take away my voice, my first thought was that I didn’t want to sound like Prof Stephen Hawking. There was no way that voice would suit me, or could ever sound ‘normal’ for my kids.

“The horrible reality of living without my voice suddenly felt very real when my speech and language therapist told me my swallow was getting worse and my muscles were weaker. She advised there was a way I could protect my voice for the future and still sound like me.

“I’d never heard of voice banking before. I spoke to Anna, my clinical nurse specialist and decided to give it a go. I’m so pleased I did. This disease takes away so much, I don’t want it to take away my voice. I don’t want to lose my identity, lose who I am, and my voice is a big part of me. I think it’s also important for my kids. My youngest is 20, and they still need to hear me, the real me and not some Americanised man. My kids have had to cope with so many changes already.

“I was given a headset and was asked to record a number of phrases. It took a long time, but once you got started it was very straightforward. I broke it up into two hour sessions, but the sessions could be as long or as short as you liked.

“The phrases it made you say were very strange. At times I wondered if I was actually reading them correctly or if my brain was playing tricks on me. The phrase about what Monika Lewinsky did in the White House was a particularly strange one! The system is designed to capture the tone and intonation of your

voice. Some of it seems very repetitive, but it really is worth it. Playing it back it really does sound like me – common and loud! My kids have had a bit of fun with it.

“When you need the programme you can run it off an iPad. It gives me some comfort to know that it is there, ready to use if I do need it. Living with the losses of CBD is hard. I’m no longer driving and have started to investigate getting a powered wheelchair. Keeping up with the constant changes takes a toil, not just on me but also my family. But, we are doing whatever we can to stay one step ahead of CBD.”

Voice banking is a process that allows a person to record a set list of phrases with their own voice, while they still have the ability to do so. This recording is then converted to create a personal synthetic voice.

When the person is no longer able to use their voice, they can use the synthetic voice in speech-generating communication devices to generate an infinite number of words and sentences. The voice created will be synthetic and not be a perfect replica of the person’s natural speech, but it will be similar.

If you would like more information please contact our helpline on **0300 0110 122** or email **helpline@pspassociation.org.uk** or speak to your speech and language therapist.





# REFLECTIONS AND A THANK YOU

To fund the best research we need access to the best researchers. Our fellowship awards allow us to attract the best clinicians, develop their scientific expertise and place them at the heart of PSP & CBD research. This commitment to supporting the careers of researchers through these awards is helping to strengthen PSP & CBD research capacity in the UK.

Four years ago Dr Ed Jabbari was awarded our Sara Koe Clinical Research Fellowship grant. Now completed, Ed looks back on the last four years of the project that was funded thanks to the support of the PSP & CBD community.

Ed said: “It feels like just yesterday when I started out as a Sara Koe PSPA Clinical Research Fellow. During my preceding years as a junior doctor, I had seen just how devastating a diagnosis of PSP & CBD can be for patients and their families. I also saw a great deal of frustration at how long it had taken for patients to receive their diagnosis, and the lack of effective treatments available. So in the summer of 2016, I jumped at the opportunity to tackle these unmet challenges as part of a PhD in Prof Huw Morris’ group at UCL, using research data from the UK-wide PROSPECT study.

“Over the next four years I was part of the UCL team which, along with teams at all the other UK sites, contributed to the growth of the PROSPECT study, which now has over 1,000 participants. Data from the study has directly contributed to us characterising the many different ways that PSP & CBD can present, and this may improve the speed and accuracy of diagnosing these conditions.

“On a personal level, I was later awarded a Fellowship from the Medical Research Council to continue my research, which led to us discovering genes that are

involved in determining PSP phenotype and survival. This may offer us new approaches to developing effective treatments. And I’m pleased to say that all of the above finally came together a couple of weeks ago when I successfully passed my PhD!

“I would like to use this opportunity to acknowledge the hundreds of PSP & CBD patients that I’ve had the immense privilege of looking after over this time. I feel incredibly honoured to have been let into your lives to gain insight into these brutal illnesses. Your willingness to sign up to research projects and trials to ‘help others’ when you were at your most vulnerable was incredible, so a massive thank you to you all.

“I look back at what we’ve achieved over this period with a lot of pride, and there is no doubt that none of it would have happened without PSPA supporters who fund the Sara Koe Fellowship and the PROSPECT study. The next step will be to use these new findings to guide us in the search for effective treatments for PSP & CBD patients, and I see great potential for this in the not-so-distant future. Even though I’m returning to my clinical training, I’ll continue to work on this alongside others in the research community (including hopefully the next Sara Koe research fellow), so it’s only a goodbye for now!”

**You can watch Ed’s thank you on our Facebook page**





# GRANDMOTHER'S PSP LEADS TO CAREER IN RESEARCH

**Imogen Tyer was just 12 when her grandmother was diagnosed with PSP. Through her grandmother's experience with the disease, Imogen saw how little was known or understood about the condition. That experience stayed with Imogen throughout her childhood.**

"Even though I was young, I knew my grandmother had been showing signs that something wasn't quite right a few years before she received her diagnosis of PSP. She'd been struggling with her balance and would regularly stutter.

"The diagnosis of PSP came in 2010 after her symptoms began to progress further and she was referred to a specialist. Unfortunately, by that point, my grandmother's symptoms were progressing fairly rapidly. She was using a wheelchair, was losing the ability to eat, had started to develop a fixed gaze and her speech had deteriorated further. She was slurring and repeating herself, so having a conversation with her was quite difficult. She tried speech therapy, but it didn't help because she was too far progressed by that point.

"I knew as a family we struggled with the fact PSP is so unknown and even the doctors and carers had little knowledge of the disease. We found PSPA's website and magazine helpful and it led to me signing up to run the London Marathon in 2021 on behalf of PSPA.

"As I progressed through education and chose Biochemistry for my degree at the University of Exeter, the lack of knowledge and understanding

of PSP led to my decision to choose the focus for my dissertation. Many of my classmates selected cancer as a topic, but due to the recent progression in research, PSP felt more topical and it gave me a great opportunity to look more into the disease.

"To gain information for my dissertation, I was able to read correspondence sent to my grandparents from the consultants and I also read lots of information on PSPA's website, in medical journals and in text books. I also spoke to tutors at university and family friends who work in the medical profession.

"It was interesting to discover that there were different phenotypes of PSP during my research. Looking at the characteristics of the different phenotypes, it also allowed me to compare them to my grandmother's symptoms, and it has led me to believe she had PSP-SL (PSP with primary progressive apraxia of speech or non-fluent variant of progressive aphasia), because of the severe issues she experienced with her speech.

"The biggest challenge I found during my research, was due to the fact PSP is so rare. This means research has been limited until recently, and because not many patients are eligible to take part in clinical trials, low numbers can mean results are often inconclusive or provide too small a sample to base findings on. There were also limited articles to help me confirm facts.

"I was pleased to gain a first for my dissertation and the work I completed for this project inspired me to apply for a Master degree. In September I started a Masters in Immunity and Infection at UCL. I'm also hoping to gain some research work experience to help progress my understanding of PSP and research as a career. I would like to try and support the research effort for PSP to make sure no one has to endure the same experience as my grandmother."



## EXPANDING OUR SUPPORT FOR PEOPLE LIVING WITH PSP & CBD

**We know how PSP & CBD can have an impact on all aspects of family life, including finances. Research conducted by the Neurological Alliance recently found that living with a neurological condition can cost up to £200 a week in extra costs.**

People with PSP & CBD usually require equipment to enable them to achieve the best possible quality of life. Devices such as communication or mobility aids can become increasingly important as people progress with their condition. While many forms of equipment are available on the NHS, we are aware there are some devices and services people may find useful that are not readily available.

To help, we have launched a new financial support service where we will provide a small, one-off payment up to £250 to help people with the extra costs PSP or CBD can cause. If you need an item of equipment such as a communication or mobility aid, or if you would benefit from some respite care, you can ask your GP or health professional to make an application to PSPA. Grants are available

to carers as well and could help provide services like complementary therapies. The application will then be assessed on the impact the item or service identified could have on the person living with PSP or CBD, or their carer.

Our Support Grants are designed to help maintain or enhance the lives of people living with PSP or CBD through the provision of an item or service. They are to provide an extra bit of help, but are not designed to be replacement for other sources of support. Since funds for the Support Grants are limited, we are only able to issue one Support Grant per person each year.

For more information about our Support Grants and how you can apply via your GP or healthcare professional, please visit

**[www.pspassociation.org.uk/supportgrants](http://www.pspassociation.org.uk/supportgrants)**

#### **PSPA SUPPORT GRANTS**

- One-off payment of up to £250 per person.
- To help provide an item or service, such as a communication aid, respite or mobility support equipment.
- Applications should be made via a GP or a health and social care professional.

#### **THE FIRST STEP IN EXTENDING OUR SUPPORT SERVICES TO PEOPLE LIVING WITH PSP & CBD**

We are determined to continue to evolve our services to do more for people affected by PSP & CBD, both now and in the future. When developing our services we need to ensure the increased costs to PSPA are both manageable and sustainable. This is why our regular giving scheme is so important to PSPA. By providing a monthly gift to the charity, our regular supporters are helping us to build core funding, plan ahead and budget for the future. By knowing how much money PSPA receives each month enables the charity to plan research spend and know how much can be invested in other areas.

PSPA supporter Anne Newton decided to sign up to a monthly direct debit seven years ago, following her father's death from PSP. Anne said: "We heard Seb Coe on the radio talking about his mother's symptoms of PSP. My mum, brother and I all looked at each other and said 'that's Dad'. Dad never received a formal diagnosis before he died, but we knew it was PSP.

"Both Mum and Dad found the support from PSPA very helpful. Since his death in 2012, I've supported PSPA through sending a regular monthly gift. I watched him suffer for several years and I'd like to think there is a way to prevent others from going through it. I know regular gifts are helpful for charities in order to plan their research and other activities.

"I've recently decided to increase my regular giving because I believe the research that is being done is very worthwhile and I'm hopeful that it will lead to treatment, and ultimately a cure for this horrible disease."

By choosing to give a regular monthly donation, you will be helping us to plan ahead and make investments to help people living with PSP & CBD. A regular gift allows us to plan for the future because we know, day in day out, that we will have a steady income stream that we can rely upon.

#### **Regular gifts allow us to:**

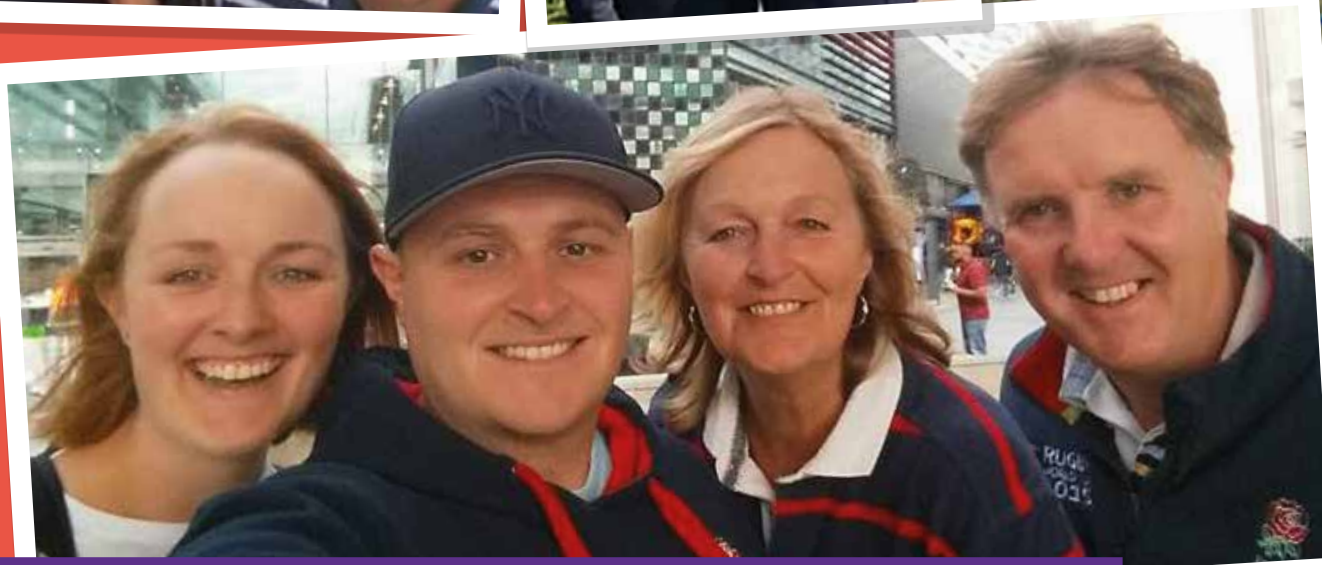
- provide grants for research projects
- extend our support services for people living with PSP & CBD
- raise awareness and educate more health and social care professionals
- develop information for people living with both disease and the professionals caring for them.

To set up a regular gift visit **[pspassociation.org.uk/fundraising/donate](http://pspassociation.org.uk/fundraising/donate)** or call **01327 322414**



**ANNE NEWTON**





## A TRIBUTE TO DAD

After the sudden death of his father John Payne to PSP, Bradley and his family decided to set up a Tribute Fund. With restrictions in place on large gatherings due to COVID-19, the Tribute Fund provided a way for family and friends to share condolences and show how much John was loved. Bradley talks about his dad and why setting up a Tribute Fund felt like the perfect way to honour him.

## “DAD’S TRIBUTE FUND PROVIDED A GREAT WAY FOR PEOPLE TO SHARE THEIR CONDOLENCES.”

“I finished work on the Friday and travelled with my wife and son 270 miles to Devon to surprise Dad for his birthday. Upon seeing us he burst into tears of joy. We’re a very close family. We’ve always spent Christmas and birthdays together.

“We spent the weekend driving up the north Devon coast, eating out and catching up. That was the 7 March. It was the last time I saw him. Lockdown happened a week later, preventing me from making the journey again, until his sudden death on 25 May from a pulmonary embolism.

“Every time I travelled to Devon I’d see how much Dad was deteriorating. It was deeply upsetting. In January his speech was limited. He was fast approaching a stage he didn’t want to get to. He’d refused a PEG and was worried about going into a home. It was hard to see my dad like this. The sporty man I knew, who played rugby and rowed was now unable to do even the simplest of tasks. Dad loved his family. He loved his home and his garden, but sadly it was all taken from him.

“In the end Dad’s death came much too soon and much too fast. He’d just eaten dinner and Mum dressed him in his PJs. He took a couple of breaths and was gone. It was a pulmonary embolism caused by his limited mobility.

“We knew something was wrong back in 2016, when Dad began to have balance problems. He was just 58, but was falling backwards and needed help walking. Mum became his main carer. It was hard to see this big, proud man become smaller, increasingly disabled and ever more dependent on Mum.

“Unfortunately, due to lack of awareness of PSP, healthcare professionals struggled to diagnose him. Eventually, following multiple investigations, he was discharged from hospital after being told there was no more that could be done. Needing an answer, my parents paid to see a private neurologist who suspected MSA.

“Mum and Dad moved to Devon to be closer to my sister. Doctors in Devon suspected PSP, but

his diagnosis wasn’t confirmed until after he died. Since it took so long to get to the bottom of Dad’s illness, he was really keen on raising awareness of PSP. Setting up a PSPA Tribute Fund for Dad seemed like a great way to honour his wishes, raise awareness and provide people who were unable to attend Dad’s funeral due to COVID-19 restrictions, a way of remembering him.

“Only 18 people were allowed to attend his funeral. The crematorium was able to live stream the funeral to a further 100 people watching online. Due to internet speeds we limited it to 100, but without it I think we’d probably of had closer to 200 watching. It was comforting to see how much Dad was loved. So many people asked how they could show their appreciation. Being able to refer them to the Tribute Fund was a great way to help them share their condolences.

“My target for the Tribute Fund was to reach £2,500, enough to have a tree planted in his name. We’ve always associated past family members with trees so it felt very fitting to do the same for Dad. I was hopeful we’d hit the target by the end of the year. We did it within a week. I shared it on my Facebook page and was overwhelmed by how quickly the donations came in. It showed us how well thought of Dad was.

“We never expected his life expectancy to be so short. We all thought we’d still get time with him. But knowing we’ve got a tree in memory of Dad feels amazing, especially since it happened so quickly. Reading all the comments about how much dad was loved and appreciated, was of real comfort to us.”

Commemorate the life of someone special while raising funds to support our work with a PSPA Tribute Fund. For more information visit [www.pspassociation.org.uk/tribute-funds](http://www.pspassociation.org.uk/tribute-funds)



## THINKING OF LOVED ONES THIS CHRISTMAS

We know for many people, Christmas can be a difficult time of year. For some, they may be grieving the loss of a loved one. For others, they may be dealing with a diagnosis of PSP or CBD, and having to come to terms with a different future to the one they had imagined.

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

Every year we are touched by how many of you send in a Christmas bauble to hang on our tree, dedicated in memory to a loved one who is living, or has sadly died from PSP & CBD. Each bauble hanging on our tree represents much loved mums, dads, grandparents, uncles, aunts, friends or children.

### THE STORIES BEHIND THE NAMES HANGING ON OUR TREE

#### JAMES HOBBS

One of the names hanging on our tree since 2011 is James Hobbs. James' daughter Rowena Brown shares why she donates every year. Rowena said: "Each Christmas we got to spend with Dad felt even more

precious than the one before. We had no idea how long we had left with him, so we were determined to make the most of every day.

"Dad was a farmer. He was a physically strong man and took the diagnosis in his stride. He didn't really understand how the condition would affect him. We are a close family and I don't think any of us were prepared for how his symptoms would progress. My brother and his wife lived with Dad, and I was close by. We cared for Dad as much as we could but his needs got ever greater and he ended up in a home.

"It was such a difficult time. I think about Dad every day. Remembering him in this way helps me to focus on the positives. I hope it helps someone else and prevents them from going through what we did all those years ago."

#### JEAN MICHIE

Stephanie Michie decided to make our Bauble Appeal part of her Christmas since her mum's death from



**JEAN MICHIE**

PSP in April 2018. Stephanie said: "Mum was a very selfless person. She volunteered in charity shops for many years and was involved in fundraising for her GP practice. She supported and donated to many charities that were personal to her. When she was diagnosed with PSP, she looked into getting involved in research, not to help her, but to help others affected.

"Remembering her in this way is something I know she would approve of. PSPA is very meaningful for our family and, having seen the devastating impact of PSP, is something I want to continue to support.

"Mum was a proud lady and faced PSP with great dignity. I'll always remember how she continued to wear makeup until just ten days before she died. She lived for her family, who were very important to her, especially at Christmas, which she would spend with her daughters, son-in-law and two grandchildren.

"As a nurse I will be working on Christmas Day. The rest of the time I will be with family and friends. Sending a bauble in my mum's name is a way for me to pay tribute to her and to make her a part of Christmas both now, and in the future."

### **STUART HANLON**

Pat Hanlon has donated to our Christmas Bauble Appeal since her husband Stuart's death from PSP in June 2016. Pat said: "I give to the Christmas Appeal for two reasons. The first is to remember Stuart. The second is to help find treatments for people diagnosed in the future.

"Watching what Stuart went through was heartbreaking, so I give to try and stop others going

**STUART AND PAT HANLON**

through what he did. His diagnosis took four years and by the time he received it he'd lost his ability to speak. In fact, it was a meeting with an occupational therapist who, by chance, had seen similar symptoms and said it looked like PSP. This led us to receive a confirmed diagnosis. Six months later Stuart had passed away.

"During his illness, he did whatever he could to reduce his progression. He tried so hard with speech therapy and physiotherapy. But sadly his symptoms progressed rapidly and he died suddenly in hospital following a fall.

"I'm grateful for the 47 happy years we had together. We certainly made the most of Christmas and would enjoy spending time off work with family and friends. Stuart loved Christmas and had a cheeky sense of humour - his interpretation of Christmas menus still make us laugh. Sadly our Christmases together are no more, but by making a donation in his memory he is still a part of mine."

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 the 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.

AMY GODFREY



TOM LAKER



## FLEXIBLE FUNDRAISERS COMMITTED TO PSPA

At the beginning of 2020 we could never have imagined that all mass participation fundraising events such as the iconic London Marathon would be cancelled. The impact this has had on our fundraisers, who've spent months training and preparing for challenges is huge.

Like many charities, PSPA expect to see a significant drop in income due to the cancellation of all mass participation fundraising events in 2020. Thankfully, our supporters have shown great flexibility in their plans, and, in the face of this global pandemic, are showing us they are there for PSPA when we need them the most. From moving to virtual events to finding new ways to fundraise, they are continuing to support our research and support programmes.

It was only when Tom Laker saw PSPA's website did he realise he actually knew someone with PSP. That was all the motivation he needed to sign up to run the London Marathon for PSPA. When the event was cancelled Tom decided to take part in his own virtual **#LondonMarathon**.

Tom said: "I always wanted to run the London Marathon ever since I watched it as a little

boy with my parents. Around four years ago at Northampton Town Football Club I saw an advert appealing for people to run the London Marathon for PSPA. When I got home I looked the charity up online and saw a story about my neighbour sharing her experiences of PSP. That was all the motivation I needed and I contacted PSPA about running the marathon in 2018.

"Back then I took a fairly relaxed approach to training. I think I did about five runs prior to the event. I'm not sure I fully comprehended how long it really was! Thankfully I completed the marathon in 4.47minutes and raised £1,800. Two years later I decided to try and beat my record and once again run for PSPA. I've pretty much gone from one extreme to the other and have been training for the last 20 months, running around five times a week. My target was to take at least an hour off my time.

"Hearing that the London Marathon was cancelled was hugely disappointing. But, I don't like to quit so I decided to do my own virtual Marathon. It's not what I had planned but I soon started to get excited about it. I put together my own route in Milton Keynes and had family and friends cheering me on. I decided to use this race to focus on beating my previous time, so that next year, hopefully, at the actual London Marathon, I can forget about achieving a personal best and just enjoy the experience."

"Charities like PSPA don't get the support they need. That's why I want to continue to support PSPA. The sense of pride you get from supporting a cause like this is immeasurable."

For Amy Godfrey the global pandemic halted her fundraising at the University of Warwick, where she is studying. Committed to supporting PSPA, Amy decided to move her London Marathon spot to 2021.

Amy said: "I think my family were surprised when I signed up for the London Marathon. I'm a science geek. I'm not known for my sporting ability and was at the bottom set for PE at school. But, I've always wanted to do the London Marathon and last year when I received an email from PSPA asking if I was brave enough I decided I was."

"Training was going well and I'd worked up to the 13 mile point around the time when the impact of COVID-19 was starting to hit. That is when training started to get especially challenging. It was hard to keep up the motivation to train when I knew the likelihood of the London Marathon taking place was remote. When it was finally cancelled I opted to pull back on my training and defer my place to next year."

"My Great Aunt died from PSP a few years ago. At each family gathering we would see her gradual progression with the disease. It was tough to watch. I'm a PhD student and I've an interest in disease progression. I looked into PSP and saw how PSPA helped my Great Aunt. As a family we've done a fair bit of fundraising for PSPA and recently my mum completed a sponsored 100km walk."

"Much of my fundraising was at the University of Warwick. Before lockdown I held a bingo night, a bake sale and a doggy de-stress day where people donated money to spend time with some dogs, including my own. I'm determined to push past the £1,800 fundraising target. Now that I have deferred my place for a year, it gives me a longer to achieve that."



### A COVID-19 FRIENDLY FUNDRAISER

Hayley Criscoli wanted to do something special on the second anniversary of her father's death. She wanted to come up with a fundraiser that she could do at her own pace and in her own time, but something that would still attract attention – perfect for COVID-19 friendly fundraiser.

"Family was everything to Dad. With Mum, he had four children and 11 grandchildren – and his loss is felt by every one of us. Watching someone I loved deteriorate made me feel incredibly helpless. While there were things we could do to help alleviate his symptoms we knew it was a fight we couldn't win. That's why, after his death, I wanted to focus on what I could do to help others living with this condition. Raising both money and awareness felt like something I could positively contribute to."

"On the first anniversary of Dad's death my sister and I both got hummingbird tattoos. For the second one, I wanted to raise both money and awareness in his memory. I decided a head shave would be the perfect way to do both. It wasn't dependent on weather, location or money, so, when lockdown came, thankfully it was unaffected."

"Friends and family thought it was a brilliant idea. I'd set an initial target of £500, and was staggered when it reached £1,500. On the day of the head shave donations were quickly mounting up. My local newspaper covered the fundraiser and friends shared it on social media. I was very touched at all the donations and messages of support."

"We still miss Dad terribly. But doing something in his memory helps me to focus on doing something positive. As a family we saw first-hand how little health professionals knew about the condition. So my next focus is on helping to educate them as a PSPA education volunteer. I know this is something Dad would approve of."





## THE IMPACT OF A DIAGNOSIS ON RELATIONSHIPS

**A diagnosis of PSP or CBD brings with it a range of emotions including fear, anxiety, tiredness and low mood. It may affect your relationship with your partner.**

It can take time for both of you to come to terms with the changes the condition may cause and the loss of the future you had planned. For some, the diagnosis may affect their relationship, their sense of wellbeing, and their sex life.

Sex and intimacy are important parts of life together but for many it can be difficult. However being open about issues around sex and intimacy can help overcome them. Honest communication can help both of you adjust to changes, allow time to talk through worries together, when you are not overtired or likely to be disturbed.

When your partner is also your carer it can be difficult to shift between carer and partner roles. Trying to separate caring activities from sexual or romantic activities, and accepting external support for some of your care can help. Give yourself time and space to remember that you are partners and make the effort to hold on to the relationship you had before PSP or CBD.

The physical and emotional impact of caring can also lead to tiredness, affecting energy levels and libido. Tiredness can have a significant impact on sexual desire and often you may feel you do not simply have the energy. This can easily be misinterpreted by a partner into them thinking you are no longer interested in sex or intimacy. Explaining this may enable you both to find a time where tiredness is less of an issue.

You might find the sexual side of your relationship becomes less important. Finding shared activities and time spent alone together can be very rewarding as priorities change. Physical intimacy might become more difficult as PSP & CBD progress, however touch

is an essential part of being human and this can be experienced, whatever your physical condition. If the acts of kissing, hugging and cuddling are important to you, make sure your partner is aware of this. Something as simple as going to bed at the same time can provide opportunities for intimate moments. If you sleep separately, finding time during the day to explore ways of being close and intimate can be a good idea.

PSP & CBD can affect the ability to communicate, which may limit intimacy. Sex is often a time when people are able to express themselves without needing to speak. You might think about developing a sign language or personal word or code that has special meaning to you both as a couple, perhaps less spontaneous, but still a helpful way to let each other know how you feel.

Most healthcare professionals understand sexual issues and will discuss these with you if asked. They may also be able to suggest medication to help with erectile function or lubricants for vaginal dryness. It's not recommended to buy medication online without talking to your doctor first.

As PSP & CBD progress life can become demanding and sometimes exhausting. It's important to find time and space to maintain loving and caring relationships. Exploring intimacy in different ways with simple intimate moments such as holding hands watching TV, brushing your partners hair, stroking their face or body and hugs can all give pleasure and the feeling of love.

### FURTHER READING

The Ultimate Guide to Sex and Disability by Cory Silverburg, Miriam Kaufman and Fran Odette.  
The Sex Book by Suzi Godson.



## UNDERSTANDING HOW PSP AFFECTS VISUAL COGNITION UPDATE

Daniel Smith and Alison Lane, Durham University are working on a three year project to develop a more complete understanding of how PSP affects visual cognition. We first shared this project in *PSPA Matters* last year. Now, one year on, Daniel provides an update.

Daniel said: "Over the last couple of years we have been conducting research projects exploring cognitive function in PSP. Our goal is to understand how PSP affects memory and attention. The first of these projects is now complete, and we have published the preliminary results in the journal *Cortex*.

"The key finding was that visuospatial attention was very severely impaired in people with PSP. Notably, people with PSP had much more severe problems completing our tests of visuospatial attention than people with Parkinson's disease. This is a potentially important finding because not many tests can reliably differentiate PSP and Parkinson's disease. These results were very promising, and the Dunhill Medical Trust subsequently agreed to fund a three-year project designed to explore whether or not tests of visual attention can be used to accurately categorise people as having PSP or Parkinson's disease. This project is the next step in the long pathway to finding a cheap, effective and reliable tool for the early diagnosis of PSP and was due to begin this summer. Unfortunately, due to coronavirus the study has been delayed, but we hope to make some progress in the new year.

"In the meantime, Dr Alison Lane and her post-graduates have been developing a survey about the use of prism glasses in PSP. Prism glasses are often recommended to people with PSP, but surprisingly little is known about how people use them, whether they like them, or whether they find them useful. Lots of PSPA members kindly helped us with the pilot version, and a new version of survey that incorporates their feedback will be ready soon. We are keen to hear about your experiences with prism glasses, so please keep your eyes peeled for it!"

### PRISM GLASSES

We have been able to provide prism glasses to people with PSP thanks to the kind support of Anne Silk, who has funded the provision of these glasses for many years. To help ensure we can continue to provide these for people in the future, please could you return any glasses you are no longer using to Freepost PSPA. This will help replenish our stock of glasses greatly.





## “WE NEED TO IMPROVE CARE FOR PEOPLE WITH PSP & CBD.”

Following his own experience of PSP and the challenges the family faced in getting their mum access to appropriate care and support, Navin Sewak has decided to use his health experience to help others living with PSP & CBD.

Navin is PSPA’s first volunteer policy adviser and is determined to raise awareness and, ultimately, help influence improvements in care for people living with both devastating conditions. Navin shares his experience and explains why it’s so important that families push for all the help they need.

Navin said: “Mum had been living with PSP for quite some time before she received her diagnosis. She was eventually diagnosed in 2016, and died just two years later. Previous to that she was living with blurred vision, unable to look down and had the fixed stare so familiar to people living with PSP.

“From the very beginning it was a struggle to get the right professionals involved in Mum’s

care. In Hertfordshire, there was no longer a neurological nurse to ensure Mum’s care was both multidisciplinary and coordinated. I decided, in order to get access to the most comprehensive care, we’d attend the clinic at UCL. While it was a good idea, it became logistically challenging. Appointments would be on different days and we could have as many as three or four appointments in one week. In time I also realised it was giving false hope to my Mum. Every time we travelled to London, she expected good news.

“I was Mum’s full time carer for two and a half years. I remember feeling like I was constantly failing. I’d turn my back for a moment and Mum would be on the floor. I’m lucky I had a very understanding employer,



but it wasn't easy. Diseases like PSP & CBD don't just affect the patient, but the whole family. Carers need to be supported and there needs to be more awareness on their health and wellbeing.

"I'm a pharmacist and my sister-in-law is a GP. We know the health system. It was because of our knowledge and experience we were able to get the right care for Mum. But even then it took a lot of pushing, a lot of calls and a lot of time. I'm acutely aware many families do not have this knowledge and it concerns me that they are not getting access to the care they need.

"My sister suggested we contacted PSPA for some prism glasses. I'd been on the website and was very impressed. The resources, particularly the ones aimed at GPs, were excellent. I know PSPA is pushing for increased awareness in primary care, and, following my own experience, this is something I want to help with.

"We travelled to a few local groups that were in our area. We were clued up, and so, we found ourselves passing on information rather than receiving it. But, it felt good to be able to use our experience and knowledge to help people understand more about the care they should be receiving. As we know, the NHS is a complicated system and incredibly hard to navigate.

"There needs to be a sufficient package of care available for people with PSP, and they should be signposted to where and how to access it. The care for people with PSP needs to be proactive, coordinated and multidisciplinary. It also needs to be timely. People don't have the time to spend waiting months for care to be put in place. It took us over a year to get continuing healthcare (CHC) funding. And we were one of the lucky ones – at least we managed to get it. I see so many people on HealthUnlocked who are struggling to get funding.

"The one thing I've learned watching Mum live with PSP is that you have to be proactive about your care. Request to be seen by a speech and language therapist, a dietician, a physiotherapist. Don't take no for an answer. Most healthcare professionals don't want to ignore you, they are simply busy. That's why you have to keep asking. Perseverance is important. I also found reading about other people's experience of PSP on HealthUnlocked, or hearing about them at PSPA support meetings useful.

"People have no idea about PSP. Those living with the condition have been dealt a bad hand. They have

a disease that suffers from poor awareness and no effective treatment. In March, along with colleagues at Pfizer we did 5KforPSPA. Over 100 colleagues took part and Pfizer match-funded what we raised. It was a good opportunity to raise not just money but awareness too. But, I want to do more. Mum's experience has motivated me to volunteer as a policy adviser for PSPA. I want to use my knowledge of the health environment to help PSPA influence government to improve care for people living with PSP & CBD. I want to increase awareness amongst MPs and I want to help families navigate the NHS. We need to bring the care experienced by people with PSP & CBD up to the same standard seen in other conditions. PSPA is in a good position to do this, and I certainly want to help."

### JOIN OUR CAMPAIGN TO END MISDIAGNOSIS

New evidence from our PROSPECT study highlights that half of people living with PSP & CBD receive an incorrect diagnosis first. Issues and delays around diagnosis mean people are potentially being prescribed the wrong medication and are left with little or no support. We are campaigning for people experiencing symptoms to receive urgent referral to a neurologist followed by an accurate diagnosis to enable them to access appropriate support as soon as possible.

### STRENGTHEN OUR CALL

Lobbying your local MP to make them aware of PSP & CBD, the symptoms and the challenges people face can have a huge impact on helping us to improve care.

### WRITE TO YOUR MP

Please write to your MP about your experience of PSP & CBD. Include you (or your loved one's) experience of diagnosis and the care you/they have received. We are suggesting you ask them to raise the issue around misdiagnosis and that it is depriving people from accessing appropriate care. To help we have a template letter on our website you can use at [pspassociation.org.uk/research/join-the-fight](https://pspassociation.org.uk/research/join-the-fight)

# TURNING YOUR EXPERIENCE INTO ACTION

## – WHAT WE ACHIEVED IN 2019/20

Every day, the devastating nature of PSP & CBD is matched by the amazing courage and commitment of our volunteers and supporters – the majority of whom have been personally affected by PSP & CBD.

Last year thousands of you volunteered, donated, ran, baked cakes and jumped out of planes raising an incredible £1.26m to support our vital work.

That funding enabled us to develop our information, significantly grow our volunteer support and invest in ground-breaking research.

### IT IS THANKS TO YOU THAT WE WERE ABLE TO:

Raise **£1.26m** to support people affected by PSP & CBD and invest in research.



Invest **£124,000** in research.



Support **5,300** people living with PSP & CBD, family members and carers.



Increase our numbers of volunteers by **50%**

Host **1,000**

members on Health Unlocked, our free online forum.



Respond to **5,500** phone and email enquiries to our helpline.

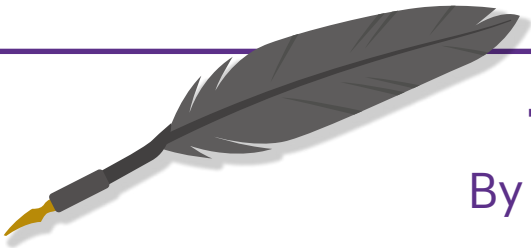


Educate **1,400** health and social care professionals.

Our **PSP & CBD** community gets stronger every year, and, in turn enables us to be stronger in the fight against both devastating conditions. This year we have ambitious plans in place including the launch of our small grants service (page 26), new research strategy (page 12) and the expansion of our volunteer support service. These activities will be alongside our work furthering research into PSP & CBD, providing people living with PSP & CBD the very best information, expanding our Local Group Network and recruiting more volunteers and supporters to our community.

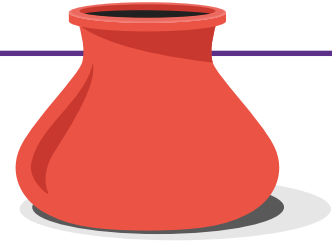
# POEM TOUCHED THOUSANDS

Louise Palfreman wrote this poem about her dad, Norman Clayton's diagnosis of PSP. The poem received a huge amount of attention, with many commenting on Facebook how much they related to it. Louise said: "My dad was especially keen that I shared my poem as he feels it tells his story and highlights just how debilitating PSP is, but that there is also hope for those diagnosed."



## TRAPPED

By L. Palfreman



Imagine having so many thoughts in your head  
Being unable to voice them so they're left unsaid

This is what's happening to my wonderful Dad  
It's making me so unbelievably sad

His mind still working and so aware  
so please think before you stop and stare

He really is the most amazing man  
His motto throughout life has been "I can"

But he's now trapped in his body and can't get out  
All I want him to be able to do is shout

He sadly can't do this anymore you see  
As his body is being ravaged by PSP

It's slowly but surely stealing him away  
With his grandchildren he cannot play

I feel such heartache that no more can be done  
And this horrible disease has taken over and won

It tears me apart, my siblings too  
That there seems to be nothing that we can do

We implore that a remedy might be found  
So, we can stamp this hideousness to the ground

He really is the most fantastic Dad  
The best we ever could have had

Amongst all this sadness anguish and pain  
My Dad's sense of humour never seems to wane

Throughout his full life he has always loved to laugh  
And often tries to smile however dark his path

"Where there is life there is hope" he'll say  
And we wish it to be true every single day

His positivity and strength I admire so much  
My Mum by his side, his loyal crutch

Now all there is to do is wait  
And leave the rest all up to fate

We'll never stop trying to find a cure  
Our quest for this so real and pure

The research continues more awareness to be had  
One day lives WILL be saved I just pray it includes  
our Dad

My children they know as I tell them all the time  
No better Grandad is out there, he really is sublime

Dad, I'll keep catching that falling star  
He's been there by my side no matter what so far

We're all in this together every step of the way  
We're here for him always and forever come  
what may



# 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 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.

