

PSP MATTERS

AUTUMN 2021



ALSO INSIDE

- How to get a good night's sleep
- Improving quality of life
- Caring for Mary

**CYCLING IN
MEMORY
OF IAN**

WHERE THERE'S A WILL...

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

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

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



**YOUR
LASTING
LEGACY
COULD
MAKE
HISTORY.**

**For more information please email
fundraising@pspassociation.org.uk**

or call 01327 322414



WELCOME

This year has been a busy one for PSPA and the PSP & CBD Community.

In this autumn edition of PSPA Matters, we will help shed some light on what we have all been up to since the last magazine was circulated in July.

As restrictions ended and more of the population became vaccinated, some of our Local Groups have started to meet up face to face again. You will see a few photos from those happy occasions on pages 18 and 19.

Also, for the first time since the pandemic began, our team were able to get out and support some of our fantastic runners at the Asics London 10k, which you can read about on page 11.

Our 2021 Research Appeal launched in May and on pages 9 and 10 you will hear from Dr Boyd Ghosh, whose team, thanks to the generosity of our donors, has been awarded the first small research grant looking into improving quality of life for people living with PSP & CBD.

Professor Huw Morris provides another research update on pages 24, 25 and 26, giving details of how the PROSPECT Study is progressing and highlighting key milestones so far.

As always, we have a number of informative articles to help support you. These include Caring for Mary starting on page 29, How to get a good night's sleep on pages 13, 14 and 15, and how OT's can help on page 34.

We catch up with some of our loyal fundraisers who help to make our work possible. This includes Elizabeth Birrell from Fife who cycled 1,000 miles for us this spring and raised more than £5,000. It was fantastic this August, to see Elizabeth's achievements recognised in The Independent's 2021 Happy List.

We hope you enjoy reading the magazine and our Christmas Card Catalogue has been included – please don't forget to get your orders in promptly to avoid disappointment.

Thank you for your ongoing support. We look forward to sharing more updates early next year.

Rowena Ironside

Chair of the Board of Trustees

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PSPAMATTERS**PSPA MATTERS NOW AVAILABLE TO LISTEN TO**

We are pleased to be offering audio versions of PSPA Matters for you to listen to on our website or download to your PC or mobile device.

Audio copies of our summer and autumn editions are now available. You can listen or download at www.pspassociation.org.uk/information-and-support/just-been-diagnosed/psp-matters/

**PSPA WELCOMES A NEW TRUSTEE!**

We are very pleased to welcome Dr Boyd Gosh to the PSPA Board of Trustees.

Boyd, who began his four year term as a Trustee at the beginning of July, said of joining the Board: "I have been involved with people with PSP & CBD and their families for many years, initially during my PhD with Professor Rowe and subsequently in my own regional clinic in Wessex. The welfare of people with these terrible diseases and their families is a matter that is close to my heart. I am really grateful to PSPA for allowing me to take part in making life better for them. I look forward to contributing to their important work."

THE PSPA CHRISTMAS RANGE

Our 2021 Christmas range is now available to buy! We have a large variety of Christmas cards to choose from as well as our very popular hummingbird Christmas tree ornaments.

This Christmas why not help spread awareness of PSP & CBD and support our vital work by shopping on our website shop or post back the enclosed order form to

FREEPOST PSPA

pspassociation.org.uk/fundraising/shop

JOIN IN THE CONVERSATION WITH HEALTHUNLOCKED

Our online forum, HealthUnlocked is an ideal resource for anyone living with PSP or CBD, carers and family members. Anyone can access the forum to read content but you must register if you'd like to ask a question or comment.

healthunlocked.com/psp

HAVE YOU EVER THOUGHT ABOUT SHARING YOUR STORY?

We are always looking for people to share their stories with us for future editions of PSPA Matters, our website and social media platforms. If this is something you would be interested in doing please contact our editor, Helen Chapman on communications@pspassociation.org.uk

CARERS VIRTUAL PAMPER SESSIONS

Thanks to the support of PSPA Volunteer Caroline Woodcock, we are currently running regular virtual pamper sessions for carers. During the sessions, which take place every two months via Zoom, carers will get the chance to meet each other and chat, as well as to be guided through a facial treatment.

If you are interested in signing up to the free pamper sessions, please email communications@pspassociation.org.uk The next session will take place on 9 December at 7pm.



JOIN #TEAMPSPA FOR THE 2022 LONDON MARATHON

Would you, or someone you know like to run for PSPA and raise valuable funds?

Our **#TeamPSPA** runners receive a fundraising t-shirt, running vest and tech t-shirt for you to wear on the day. We have a dedicated WhatsApp chat and Facebook group for our London Marathon runners of the past, present and future. Your efforts will help improve the lives of people living with PSP & CBD by funding services including the PSPA Support Grants and Voice Banking service.

Are you up to the challenge?

Go to our website and fill in the application form now! pspassociation.org.uk/events-list/london-marathon-2022 We will then be in touch about the status of your application and next steps. The minimum sponsorship we ask runners on a charity place to raise is £2,500 and there is a non-refundable £99 joining fee.

If you have your own place for the 2022 event, we'd love for you to use your place to join **#TeamPSPA!** Make your run count by raising what you can, wearing a PSPA t-shirt or vest too!



MAKING SOME NOISE FOR PEOPLE LIVING WITH PSP & CBD

We are excited to have been selected to be one of 60 small charities being supported by Global's 2021 Make Some Noise Campaign.

On 8 October, Make Some Noise Day, we rallied our supporters, far and wide, to raise awareness of PSP & CBD across the UK.

During the day we shared details about the support Global Make Some Noise are providing as well as highlighting how our services have helped people living with PSP & CBD using the campaign hashtag #LostWithout

Thank you to everyone who helped us maximise this opportunity to Make Some Noise on 8 October for the 10,000 people living with PSP & CBD.

PSPA HELPLINE NOW AVAILABLE 9AM TO 9PM

In July we began a six month trial extending the Helpline opening hours to 9am to 9pm, Monday from Friday.

The trial will enable more people living with PSP & CBD and carers to access our specialist information and support, including our PSPA Support Grants and funding for SpeakUnique Voice Banking services.

If you would like to take advantage of the extended hours, you can contact the Helpline on **0300 0110 122** or by emailing helpline@pspassociation.org.uk



LOCAL GROUP MEETINGS IN SCOTLAND

Our local group in the North of Scotland is currently on hold as we are without a volunteer to coordinate the group. If you are interested in helping us to get the group started again please contact volunteering@pspassociation.org.uk

The next meetings scheduled in are **West of Scotland**
5 November at 3.30pm
6 December at 3.30pm

East Central Scotland
2 December at 3pm

If you would like to dial into either meetings to chat with other people living with PSP or CBD, please contact our Helpline on **0300 0110 122** or by emailing helpline@pspassociation.org.uk

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

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





A ROSE BY ANY OTHER NAME

Explaining PSP to friends and family can be difficult. Since the condition isn't well known, describing the symptoms and how they impact on your family life can lead to long explanations and blank faces. Here Sue Wilsea shares her thoughts on her husband's diagnosis.

"My husband Mike, like many others with PSP, was originally diagnosed with Parkinson's. When we told family and friends, we found this condition was readily understood. It was a different story when Mike's diagnosis was changed to PSP.

To start with, I'd certainly never heard of PSP before Mike's diagnosis and I'm assuming that would be the same for most people. Indeed, even some medical staff might not have come across it. As the 2019 annual report for PSPA says, 'We know lack of knowledge and awareness of PSP... can hamper health professionals' ability to provide good care.'

As a condition, you can break down the three different words. Progressive speaks for itself but I'm ashamed to say that before coming to write this I hadn't known what supranuclear meant. Even worse, I'd misread supra for super which lent it a jolly hockey sticks, Enid Blyton vibe! As for palsy I'd only heard the word used with regard to Cerebral Palsy and Bell's

Palsy apart from in Shakespeare plays (apparently, the Bard was very accurate in his descriptions of a wide range of neurological conditions).

And with the acronym, if you Google PSP, the first thing that comes up will be Playstations! It's also not a memorable acronym and easily confused with similar ones. 'Remind me what your husband has,' someone once asked, 'I know it begins with P... I know, PSE, wait that's not it, PPE, no that's to do with Covid-19...PMT?'

So, what do you tell people outside one's close circle of family and friends? It might seem easiest to stick with the Parkinson's tag to avoid having to explain what differentiates PSP, particularly since the condition is one of several so-called Parkinson's Plus syndromes. But this wouldn't help raise awareness or indeed understanding. In addition, as I discovered myself, mentioning Parkinson's could lead to comments about a lack of a tremor, which



is often the first symptom people tend to think of. It can also be followed by the person letting you know about someone they know of who is living with the condition. I was told by one acquaintance how their neighbour's cousin had Parkinson's but had walked the Pennine Way. I mean, that's great stuff and very well done to the person concerned but it does serve to suggest that, with the right attitude, symptoms can be slight and/or manageable. Added to that is the business of deciding who is in the inner circle of those who are told the truth while remembering who you've said what to. Like many people, I'm a rotten liar and blush when I tell porkies!

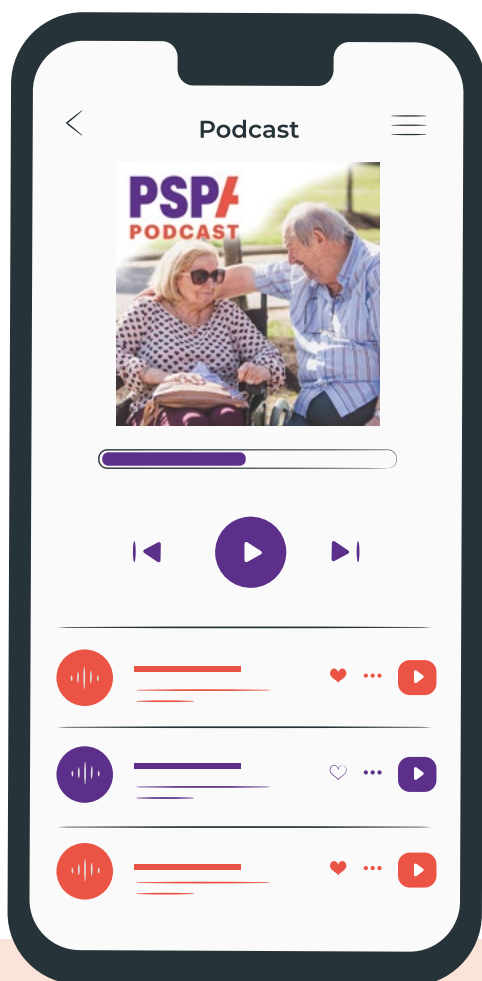
Alternatively, if you decide to be open about PSP (and have explained the acronym) what more should you say about it? The reality of PSP symptoms and prognosis can be pretty grim: the best thing I've found is to advise people to look it up for themselves. Two of Mike's regular carers were great in the way they researched the subject in their own time and were therefore able to recognise early

signs of the condition progressing, for example difficulty with swallowing, as well as filling in any other visitors to the house!

Some might argue that it's only a label so what does it matter? All I know is that the time before we were given the original label of Parkinson's was an anxious one with no explanation for a random collection of minor yet worrying symptoms and behaviours, seemingly only noticed by me. Hence there was a strange sense of relief when a label was assigned, not least allowing me reassurance that I wasn't imagining things! Then, after about a year when Parkinson's medication had little or no effect on Mike, the consultant amended his diagnosis to PSP. While I completely understand that others might not feel the same, we both took comfort in a label which could explain what was happening and why.

Anyway, my theory is that only Pretty Special People have it!"

"I'D CERTAINLY NEVER HEARD OF PSP BEFORE MIKE'S DIAGNOSIS AND I'M ASSUMING THAT WOULD BE THE SAME FOR MOST PEOPLE. INDEED, EVEN SOME MEDICAL STAFF MIGHT NOT HAVE COME ACROSS IT."



PSPA PODCAST FOR CARERS

On 10 June, we launched the PSPA Podcast to help inform and connect people caring for a loved one living with PSP or CBD.

The podcast launch was made possible thanks to a grant from the Pavers Foundation in memory of Mary Youll. Pavers employee Beth Morgan-Henderson, applied for the funding to support PSPA's podcast because she has first-hand experience of PSP. Beth's aunt was diagnosed in early 2018 and sadly passed away from the condition in December 2020.

Beth said: "As a family we've experienced first-hand how incredibly difficult it is to care for a person living with PSP due to a real lack of awareness of this debilitating disease. So, with the amazing support from the Pavers Foundation we felt the podcast would offer the most benefit and long-term gain to raising awareness of PSP & CBD."

Thanks to the generous grant, PSPA secured support in recording, editing and publishing podcast episodes where Liz Sturgess, one of PSPA's Helpline Care Navigators, speaks to different carers about their experiences of PSP & CBD as well as any ideas and tips they have picked up along their journey.

The podcast is monthly and currently there are five episodes you can download to listen to. These include:

- ▶ **Episode one** An introduction to the podcast with Beth Morgan-Henderson from Pavers
- ▶ **Episode two** Getting support as a carer with Julia Tickridge
- ▶ **Episode three** Delayed diagnosis with Denise Hunt and Navin Sewak
- ▶ **Episode four** Caring for a parent with Claire Wells
- ▶ **Episode five** Explaining PSP to your friends and family with Sue Wilsea

Future episodes planned for this year will include voice banking, house adaptations and keeping your loved ones involved this Christmas.

So far, the podcast has been received really well, with it being downloaded 832 times since its launch, and we hope as we produce more episodes, it will grow in popularity.

DOWNLOAD AND LISTEN TO THE PSPA PODCAST

You can download the podcast from our website: pspassociation.org.uk/information-and-support/for-carers/pspa-podcast-for-carers/ Or on Anchor App or Spotify – just search PSPA Podcast.

If you have any suggestions for a topic you would like to see covered by the podcast, please send your ideas through to communications@pspassociation.org.uk



RESEARCHING THE IMPACT OF MULTIDISCIPLINARY APPROACHES

In May we launched our 2021 Research Appeal to fund small grants to help healthcare professionals and researchers look into how to improve the quality of life for people living with PSP & CBD. Thanks to your support Dr Boyd Ghosh and his team in Southampton have been awarded the first grant to research the impact of multidisciplinary team approaches.



"It is 8:30am on Friday morning and I have just arrived at our regional clinic for people with PSP, CBD and Multiple System Atrophy (MSA). Although the clinic starts at 9am, our clinic coordinator Jade Donnelly is already there. We have time to discuss patients who have contacted her since our last clinic, regional hospice meetings she has attended and therapy, wheelchair and Continuing Health Care referrals she has made. It is a holistic multidisciplinary approach that Jade, Dr Luke Massey, our other Neurology consultant, and I have developed over the last six years or so.

We have been lucky in getting support for our clinic from a long line of clinical leads and care group managers in our trust, most recently Gail Doran. Our patients seem to appreciate our clinic and our clinic coordinator, and it appears that our patients have to access emergency care less often. However, I know that other clinics around the country struggle to convince managers and colleagues of the benefits of this type of clinic. In particular, managers would like to know if, in today's cash strapped NHS, a clinic like ours will reduce the use of expensive emergency NHS resources and allow patients to access care in a more pro-active way.

Usually in a situation like this, there are articles in medical journals enabling us to show these types of benefits, but in this instance there are very few. It is difficult to persuade big research councils and funders to pay for research exploring this type of question for rare diseases like PSP & CBD, despite the importance for people with these diseases and their families.

However, I was lucky enough to get some funding from PSPA to start answering just this question. We will look at quality of life for the person with PSP or CBD and the amount of health resources that people use, amongst other measures, in our population of patients. Importantly though, our clinic covers a wide area and we have patients coming from Somerset to Guildford and Salisbury to the Isle of Wight. In this region the ability for patients to come to our central clinic varies and the provision for a local Parkinson's nurse, therapy support and other services differs from area to area. We will use this variability to see if we can find the differences for people who do and do not have access to certain services. For example, patients may have a lot of benefit from having a health coordinator, in terms of easy access to advice, easing concerns therefore enabling pro-active access to care and reducing emergency admissions to hospital.



“THIS FUNDING FROM PSPA IS AN IMPORTANT FIRST STEP ON THE PATH AND HOPEFULLY AT SOME POINT IN THE FUTURE ALL PATIENTS IN THE UK WILL HAVE ACCESS TO SPECIALIST SERVICES LIKE OURS.”

We may also find that having regular access to a physio and occupational therapist enables people with PSP or CBD to stay at home with their family rather than having to go to a care home.

In the NHS, many disease groups are legitimately clamouring for extra resources claiming that these resources will reduce costs in the long term. In this situation, it is very helpful for health professionals who are trying to set up clinics like ours to have objective evidence for the benefit of the clinic, rather than just second hand reported comments saying how useful people have found them. What can often help is having some internal NHS guidelines stipulating that this type of clinic should exist to care for these patients. For England, the National Institute for Health and Care Excellence (NICE) provides this support, other agencies support health care in different regions of the UK. If NICE publish guidance stating that a particular clinic or service should exist for patients, then every trust in England will have to audit what they do and if they don't have this service, take all steps they can to provide it.

At the present time, no NICE or equivalent guidance exists for services for patients with Atypical Parkinsonian Syndromes (APS): diseases like PSP, CBD and MSA. NICE would need research studies that are as rigorous as possible to decide what they should recommend. Our study may not fit their usual rigorous criteria, but it may

provide supplementary evidence. However, more importantly, it may give us some pilot data that would enable us to go to a research council or other big funder to obtain funds for a much bigger and much more rigorous study. NICE will want a few such rigorous studies, in different regions, to be sure that they should recommend specialist MDT clinics for patients with PSP & CBD, as they have done for Motor Neuron Disease and Parkinson's disease. There is plenty of work still to do to get to that point, but this funding from PSPA is an important first step on the path and hopefully at some point in the future all patients in the UK will have access to specialist services like ours.”

2021 RESEARCH APPEAL



There is still time to donate to the 2021 Research Appeal.

If you would like to donate towards research looking into how we can help improve the quality of life of people living with PSP & CBD, you can do so

Online: www.pspassociation.org.uk/2021-research-appeal/

By phone: **01327 322414**

By post: **Send a cheque to PSPA FREEPOST**



**#TEAMPSPA TAKE ON THE
ASICS LONDON 10K**

On Sunday 25 July, seven #TeamPSPA runners took to the streets of London for the Asics 10k run.

It was a great day to get out and cheer all our runners on, who together have raised more than £3,600 for PSPA. Here the team share their experience of the day.

SHEENA SUDERA

"Thank you for letting me run my first ever 10k for such a personal charity to my family. We had an amazing day and an experience I'll cherish. Hopefully my grandfather will be proud from wherever he is watching!"

PANAY DUNN

"I signed up to the Asics 10K because my husband's cousin's husband Brian developed PSP and eventually died of it in 2015.

I wanted to raise awareness and money for this excellent charity which helped provide information and practical support to Brian and his family. This is my 5th run for PSPA, the 1st being in 2016. This year I raised £665 and over the five years £3,285.

It was a great feeling and I was humbled by all the supporters and very grateful for all the generous donations received. I hope this will in a small way help people with PSP."

RACHEL ALDRIDGE

"The ASICS 10km was my first ever race as I only started running in March 2020 after the first lockdown. I always figured that if I was going to run a race, I'd really want to do it for a cause close to my heart and this is where PSPA comes in. My mum sadly lost her battle with PSP a few years ago now. PSP is a pretty cruel disease but with research and funding and a little hope we can work towards a future without it or with more effective treatments. Giving people like my mum lots more time to create happy memories with her family and grandchildren."

"WE HAD AN AMAZING DAY AND AN EXPERIENCE I'LL CHERISH."





HOW TO GET A GOOD NIGHT'S SLEEP

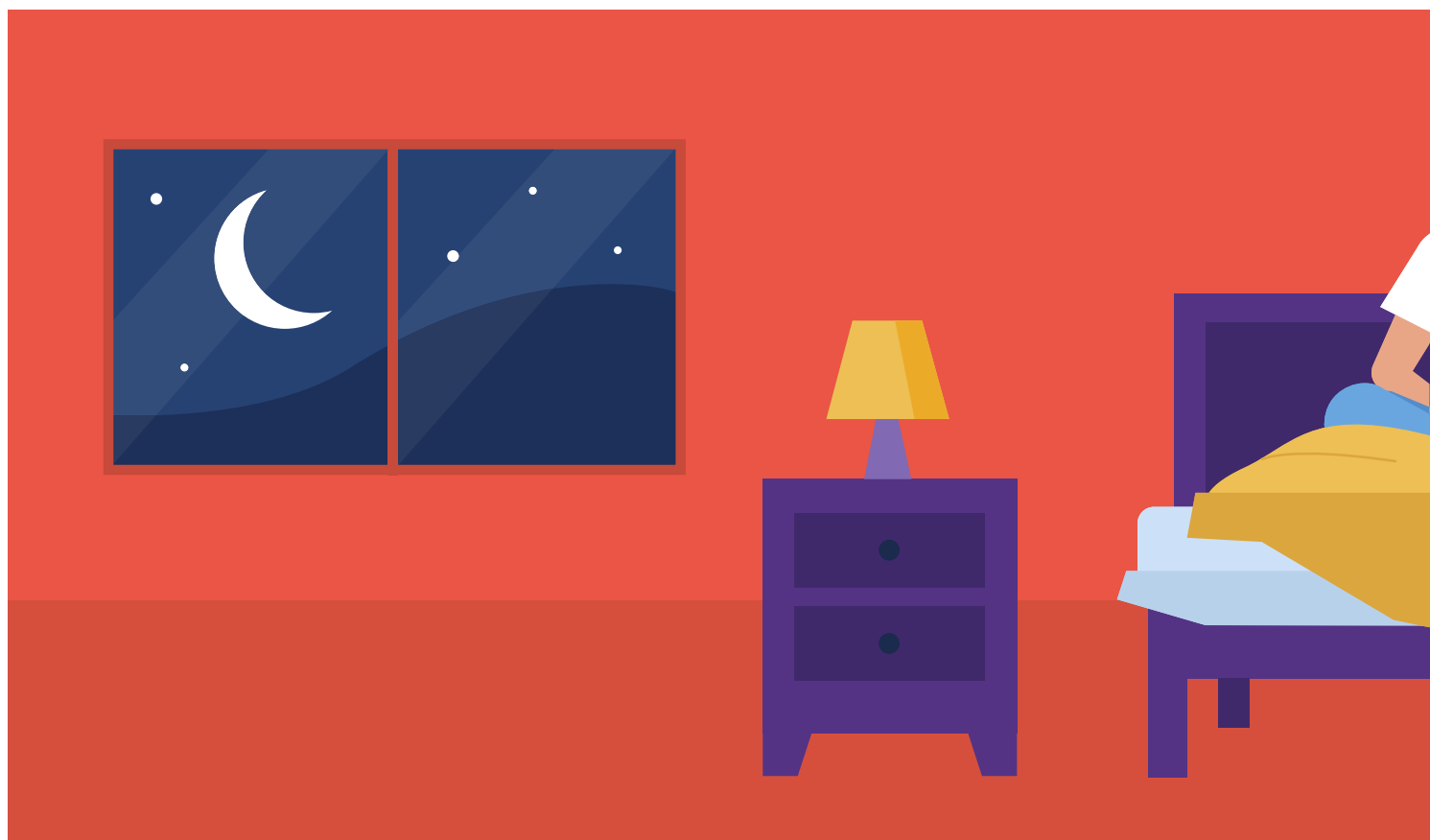
We all know that sleep is important in helping us maintain good physical and mental health.

Sleep disruption can be common with neurodegenerative conditions such as PSP & CBD as they can affect the brains' ability to regulate sleep/wake behaviour.

Insomnia which includes difficulties with falling and staying asleep is something which occurs at different times and for different reasons, you may be feeling emotionally overwhelmed, such as when awaiting or first receiving your diagnosis. Anxiety, relentless replaying of a day's events and heightened emotions

may all interfere with your sleep. Another common cause of insomnia is a change to daily routine, this may be a change in your care support, maybe a change in sleeping arrangements, such as moving to downstairs living or use of a hospital bed.

Good sleep hygiene can often make a difference and enable sleep to come more easily. This may take time and determination. It isn't a quick fix, however following steps to good sleep hygiene, can over time, help to improve sleep.



» SLEEP HYGIENE STEPS CAN INCLUDE:

- » Keep a regular sleep routine, go to bed at the same time and get up at the same time (weekends included)
- » Keep the temperature in your bedroom comfortable. 18-24 degrees celsius is ideal
- » Keep your room dark and quiet enough to encourage sleep. Try thicker curtains (keeping a night light in the hallway/landing, should you need to use the toilet in the night)
- » Try to exercise each day, a short walk, chair-based exercise. Avoid exercising in the evening
- » Give yourself at least an hour to wind down before going to sleep, have a warm bath or shower and do some gentle stretches if you are able
- » Music can help if soothing, listening to a podcast or relaxation CD can be helpful
- » Keep your bedroom just for sleeping and sex, where possible avoid using mobile telephones, tablets and watching TV in bed.

There may be other barriers which are affecting your ability to sleep well, let's look at these:

» EATING AND DRINKING

Don't go to bed either hungry or too full. Try to eat your main meal of the day at lunchtime and have a

lighter evening meal at least three hours before bedtime. Caffeine should be kept to a minimum during the day, try not to drink anything containing caffeine in the evening. Caffeine can prevent deep sleep and affect the process of falling asleep.

Alcohol should also be avoided in the evening, whilst a glass of wine or beer may make you feel drowsy, it won't improve your sleep and can disturb sleep patterns as it is a stimulant.

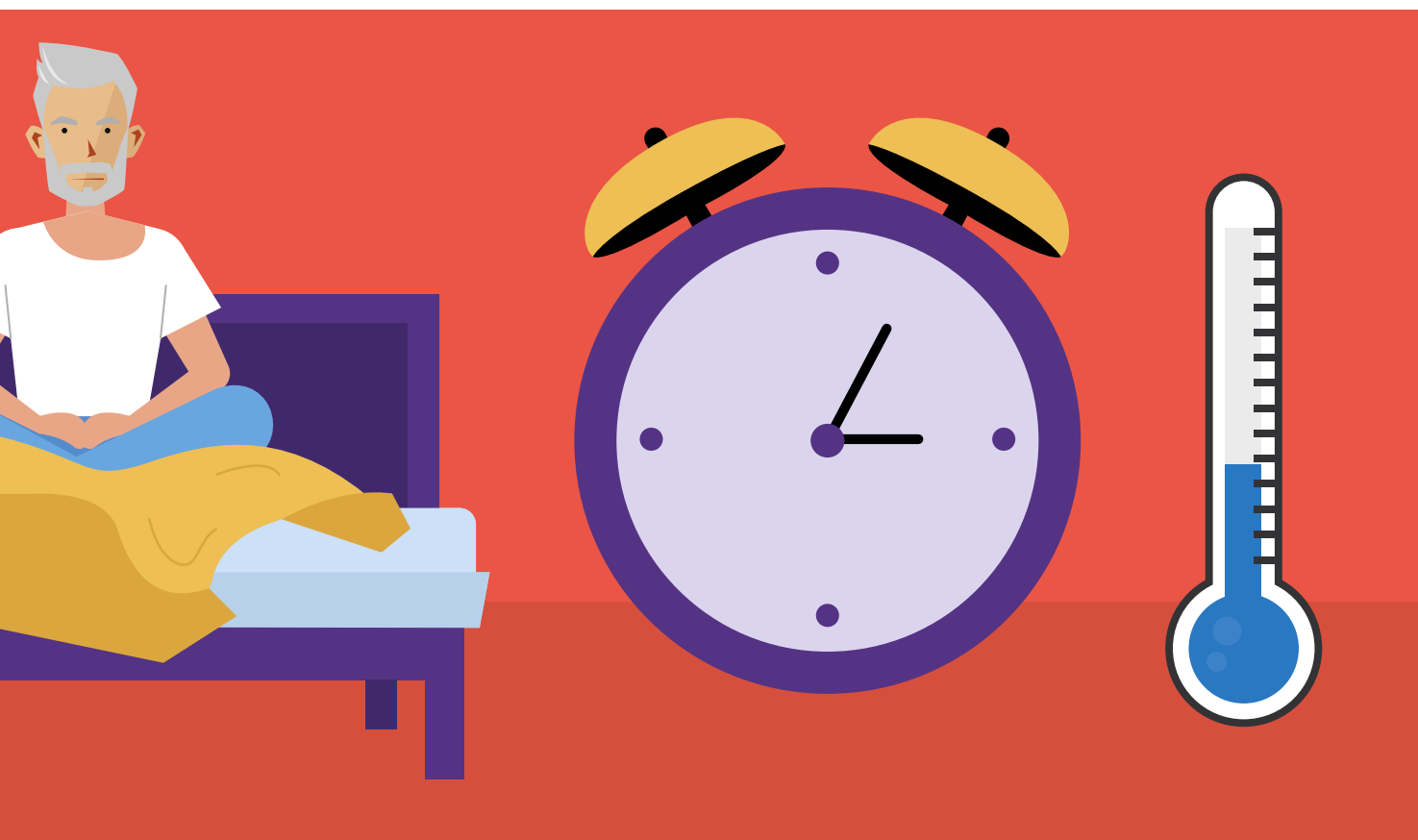
Warm milky drinks and herbal teas can help as part of the wind down process before bed and form part of your going to sleep routine.

» ALTERATIONS IN YOUR BODY CLOCK

As PSP & CBD progress, alterations in your body clock are common. This may include being awake at night and asleep during the day.

Try to manage daytime naps where possible. Consider setting a timer or alarm so you don't sleep all morning or all afternoon.

Try to avoid the 'danger nap' time of late afternoon to early evening as this can impact on your ability to get to sleep later.



» DIFFICULTY WITH MOVEMENT

Reduced movement and stiffness or rigidity associated with PSP & CBD can make moving in bed difficult, getting into a comfortable position for sleep can be tricky and therefore impact on your ability to get a good night's sleep. Discuss this with your occupational therapist (OT) who will be able to suggest ways in which you can help yourself to move about in bed, grab rails which can slide under the bed can be provided, slide sheets are also helpful. Satin sheets or satin night clothes can help you to move more freely in bed, however, avoid using both at the same time as this may make it more difficult not easier to move about.

Your OT can also advise on sleeping positions, pillow placement and a suitable mattress for you.

» PAIN AND MEDICATION

If you are experiencing pain at night-time and it is affecting the quality of your sleep, discuss this with your Neurologist and/or Parkinson's Nurse Specialist. Depending on the type of pain and cause, appropriate pain medication can be prescribed.

Restless legs can often be a problem. There are a couple of ways to try to alleviate this, a

weighted blanket can be helpful as can massage. You should discuss with your Neurologist or Parkinson's Nurse Specialist as some Parkinson's medications may be helpful.

Sleeping medication can be prescribed, usually in the short term only. Discuss how a lack of sleep or disturbances to your quality of sleep are affecting you with your GP or Neurologist who may feel that prescribing sleep medication would be beneficial to you. They may ask you to keep a sleep diary to help them to understand the best way of supporting you and to work out if there are any contributing factors to your PSP or CBD which may be affecting your ability to sleep, which can be addressed.

Further information about sleep hygiene can be found at www.nhs.uk/every-mind-matters/mental-health-issues/sleep/



ADAPTING TO LIFE LIVING WITH PSP

As symptoms of PSP & CBD progress, changes to your living environment may be needed. John Forth and his wife, Bonita, are moving to a new bungalow which they are adapting to ensure their needs are catered for, now and in the future.

“My wife, Bonita, was diagnosed with PSP in October 2019 but she had been experiencing issues with her balance and speech for several years before, but no one seemed sure what was wrong.

We went through a round of investigations and tests for four years before the diagnosis was made, after Bonita began having falls in 2016. It was a particularly bad fall in 2019 which made the doctors realise it could be something neurological. After this, Bonita was referred to a specialist in Edinburgh who confirmed it was PSP, but by this point, she was already using a wheelchair to get around and a turn and transfer device for moving in between.

After another bad fall in 2020, which resulted in a head injury and fractures, we realised we needed to make our home more accessible. We had already moved from Scotland to be nearer to family, into a rented bungalow to which we could make no significant changes.

With support from the Local Authority, we identified this bungalow wasn't big enough

for Bonita's changing needs. In particular, the corridors weren't wide enough for wheelchair use, and the bathroom not big enough for Bonita, a shower chair and carers too.

Luckily, we found another bungalow after much searching and a lot of compromising in the East Riding of Yorkshire, which had the kind of space we were looking for but no large bathroom.

Understanding how Bonita's PSP will progress, and when, is difficult as the condition seems to be very particular to the individual so I was unsure where to start when thinking about adaptations. PSPA and Google have been really helpful though in establishing the starting points and meant I was asking the right questions to the right people. PSPA sent across a big list of considerations, which helped focus me in terms of looking at things like width of door frames, height and functionality of fixtures and fittings, level entry into the home and into the back garden, as well as how any mobility or daily aids might fit in alongside our regular furniture.

This led to plans for the creation of an extension bathroom to the new bungalow as well as for decking in the garden, to help provide a level entry so Bonita can enjoy the back garden in the summertime.

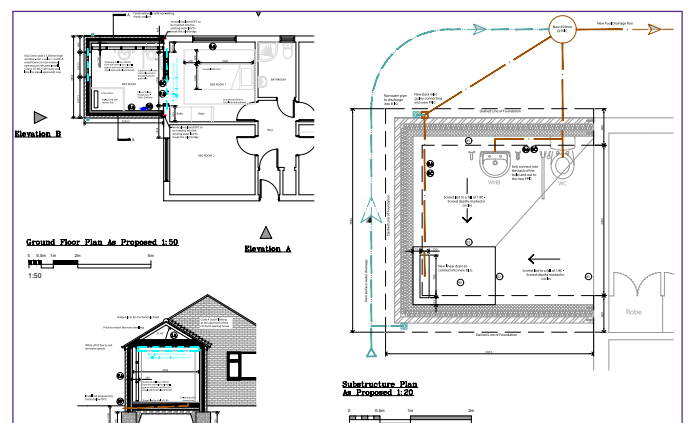
To progress these ideas, I met with an architect in April this year who drew up plans for the proposed wet room in the new bungalow. The wet room adaptations are self-funded and include a 1500 by 900 walk in shower, a wash basin with a hand-held shower head to use over the basin and loo, and a smart toilet with easy flush functions and enough room to fit a Sara Steady patient moving device.

Work will be needed to reinforce the ceiling in our bedroom and add a ceiling track for a patient hoist that will inevitably be needed. There was a lot of toing and froing between architects, occupational therapists and us at this point, as ideally, we wanted to adapt the new property before we moved in. Due to Covid-19 and drawn-out legal problems this has yet to take place. We have now taken possession of the property and preparatory work is underway. However, the Local Authority are unable to send out an occupational therapist to assess Bonita and the property until we move in. This is to happen now that we have the bungalow.

Keeping on top of the purchase of our bungalow and progressing the modifications has meant a lot of multitasking, but throughout I've just pressed on and kept smiling. It will be worth it in the end as the new home will be "wonderful." You should have seen Bonita's face when we got the keys."



"AFTER ANOTHER BAD FALL IN 2020, WHICH RESULTED IN A HEAD INJURY AND FRACTURES, WE REALISED WE NEEDED TO MAKE OUR HOME MORE ACCESSIBLE."





PSPA LOCAL GROUPS - GETTING BACK TOGETHER

Over the past 18 months, up and down the country our Local Groups have continued to meet and offer support and friendship via Zoom, WhatsApp and the good old telephone. We know how much this has helped people feel less isolated and brought people together at a time when we all needed that bit of extra support.

We would like to take this opportunity to thank all our volunteers and our Helpline Care Navigators for facilitating the meetings and taking a crash course in online meetings. There were a few hiccups along the way when we first started but we got there in the end.

We know not everyone found our virtual Local Group meetings easy to access or felt comfortable talking to a screen and this has meant that many

people have not seen their 'local group friends' for some time. PSPA are encouraging our Local Groups to cautiously start to meet in person and provide face-to-face support again. Each group will go at their own pace, and there is no pressure for people to meet face-to-face if they do not wish to. You will find people are still meeting online so you will have access to the option that works best for you.

Our Local Group Coordinators have been asking their groups member what they would like to do. Betty Peers, Woking Local Group Coordinator and Jenny Knight, Local Group Coordinator for Coventry & Warwickshire came up with some suggestions of where to meet outside and arranged their first face-to-face meetings in over a year.

The Woking Local Group visited RHS Garden Wisley which is a beautiful location especially on a sunny summer's day. As you will see lots of people turned up

**“WONDERFUL TO BE
IN THE COMPANY OF
OTHERS AGAIN.”**

“ZOOM WAS BETTER THAN NO MEETING, BUT NOT A SUBSTITUTE FOR MEETING FACE TO FACE.”

to meet for tea, cake and a chat. People were mindful to socially distance but still had a lovely time catching up with old friends and enjoying the sunshine.

Coventry & Warwickshire Local Group were able to meet at Dobbies Garden Centre on the outskirts of Stratford-Upon-Avon. Jenny said “We had planned to meet in Coventry War Memorial Park but the weather was showery so we decided to meet in the garden centre. The staff were very obliging and allowed us to rearrange some of the tables in the outside covered area so we could sit as a group”.

So, we can see things are slowly getting back to normal. Some of the groups may not meet face-to-face until next year but we will continue to work with our Local Groups to offer continued support in a safe environment for everyone.

Please also remember that we now have a Newly Diagnosed Group, CBD Group and a Youth Support Group that are meeting virtually. If you would like more information on the meeting dates for any of the meetings please visit our website or contact the helpline on **0300 0110 122** or **helpline@pspassociation.org.uk**

We send out regular invites to our Local Groups, if you are not receiving these and would like to, please get in touch with the helpline to update your details.

Our Local Groups provide support and friendship to local people affected by PSP, CBD, their families and carers.

We are looking for volunteers to run local groups in the following areas:

North of Scotland – Sussex – Dorset – Kent – Northampton – Newcastle

If you are interested in volunteering as a Local Group Coordinator, please contact **volunteering@pspassociation.org.uk**





ANNUAL AWARENESS RAISING CHALLENGE FOR IAN

After her husband passed away from PSP seven years ago, Elizabeth Birrell, from Fife has made it her mission to raise as much awareness of the condition as possible. Here Elizabeth shares details of her 2021 challenge.

"Ian was diagnosed with PSP in 2009 after experiencing a few symptoms such as falling backwards, which he thought was strange but passed it off as just one of those things.

It wasn't until he started to slur his speech and experiencing a feeling like his tongue was too big for his mouth, which led him to seek advice from the GP. Initially Ian was just told to come back in a few weeks if the feeling persisted.

When the slurring got worse, and family members began to not understand him, we called for an ambulance fearing what was wrong. This led to a two-week stay in hospital for various tests and investigations, after which the specialist said it could be some type of Parkinsonism. Six weeks later and we received the diagnosis of PSP. As PSP was so little known, when Ian passed away I was inspired to raise awareness of the condition so more people could spot the signs and symptoms sooner.

As Ian was a Rotary member, I started to join them on their annual coastal walks in 2010, raising funds for PSPA as well as awareness of Ian's story to help increase the number of people who know about PSP.

I completed about ten walks and I also would hold coffee mornings and street parties locally in Cellardyke in Fife, raising in total around £70,000 as well as to share PSPA's Red Flag posters with GPs and health professionals in the area.

When lockdown hit last year and the annual coastal walk was cancelled, I started thinking about what I could do this year to continue to raise awareness of PSP, considering the restrictions and the impact COVID-19 has had on charities.

I had developed an interest in cycling since March 2020, which I used to do early in the morning to watch the sunrise whilst I was out, and since I found it so enjoyable it seemed like the perfect challenge to set myself and honour Ian's memory in the process.

Starting in April 2021, I began my challenge of cycling 1,000 miles for PSPA, aiming to reach the target distance before the end of June.

I was cycling as much as I could, weather permitting, notching up around 30 miles each outing, mainly cycling alone but with a few family members joining me on some of the last cycles.

I completed the challenge earlier than anticipated, in 31 days on 9 June and couldn't quite believe the amount of support I received as I did it. In total, through the cycle, I raised £5,323 for PSPA from sponsorship from friends and family which is amazing. The local magazine, The Courier, also covered my cycle and experience of PSP too which greatly aided my awareness raising.

I really enjoyed the cycle but needed a well-deserved rest and massage following the challenge."

You can view some of Elizabeth's cycle route and support her fundraising too at **www.justgiving.com/fundraising/ianbirrell2021**





“ACTIVE DECISIONS EARLY ON MEANT PSP DIDN'T DEFINE MUM”

Following the death of their mum, Julia Stokes' sons Oliver and Henry share how a positive mind frame, making key decisions and supporting others helped Julia to triumph over PSP.

“Mum was beautiful, elegant, loyal, kind and strong minded. And a bit of a pioneer in many respects. In the early sixties she was one of BOAC's (now British Airways) first air stewardesses, travelling the world, taking new cultures and different ways of living in her stride.

It was thanks to her travels she met dad, an engineer, during a stopover in Hong Kong. Once married, and with a young family in tow, mum thought nothing of moving her life to Saudi Arabia when dad's job required.

She was very social and being both dutiful and helpful, she made the best of things, wherever she was.

As our parents retired, they moved to Rutland where mum thrived, attending church regularly, being part of the community and enjoying the simple things pottering around in her garden, or volunteering.

Unfortunately, enjoyment of their retirement was affected when dad was diagnosed with diabetes and neuropathy around 2000. Mum was a brilliant carer

for dad though, always putting his needs above her own. As she did with everyone.

PSP hit quite quickly after my dad passed away in 2011.

With dad's illness being our central focus, we don't know if we missed the initial signs, but symptoms such as slurring words, being a little vacant and falling backwards, seemed to build very quickly in the following year.

Diagnosis did take a while. Possibly due to mum's age, she was around 78 years old at the time, we passed some of the symptoms off as signs of getting older. It was difficult too, because in between the symptoms, it was hard to see there was anything wrong with mum.

But mum accepted her diagnosis and prognosis of the condition quickly, and certainly didn't let it stop her living her life.

We are very proud of how mum handled it all and as a family we drew great strength from the fact she actively made decisions about her life, such as care

“MUM WAS BEAUTIFUL, ELEGANT, LOYAL, KIND AND STRONG MINDED. AND A BIT OF A PIONEER IN MANY RESPECTS.”

needs and her contribution to the study of PSP. She benefited greatly by not letting PSP define her.

She maintained, if not grew, her social circles. She was so friendly and helpful, it was easy for her to accumulate new people in her life.

She also didn't shy away from adventure, bravely choosing to take the tube instead of getting a taxi when she visited London.

Mum lived with the increasing symptoms admirably and independently, until a rising number of falls led to her announcing it was time she moved into a care home. Naturally choosing the same one my dad spent his latter years in.

Even though she broke her arm just before the move, and was in a lot of pain, she took it all in her stride, never feeling sorry for herself and always looking on the bright side. Whenever asked how she was, her response was always exactly the same, 'better than some poor folk around here.' This positive self-talk helped her and us deal with PSP, keeping PSP out of our relationships and preserving mum the way she really was.

When mum was losing bodily function, cognitively she was still her. She could always think clearly and remember people and events, which we were very thankful of.

Most of all, her sense of humour remained intact. Even when she was unable to speak or see, I could still make her roar with laughter by recounting memories of our family, and our lives.

We are convinced that mum's early decision to aid research by taking part in studies led by Professor James Rowe, and to donate her brain, won her a mental victory, which gave her and us great strength. If knowledge is advanced by even the smallest amount by mum's donation then that difference will ultimately be a small but vital part of the defeat of PSP.

Although a difficult decision for the family, we all felt immense respect and pride towards mum for this. Mum also became involved with PSPA, regularly donating to the charity and supporting their work. As a social person, contributing to the PSPA community, made her feel helpful and like she was taking control of the situation, enabling her to define her own relationship with the condition.

Mum's determination to make a difference not only helped her, but as a family, it has given us a way of preserving mum's memory and a legacy to focus on, rather than the injustice of PSP."



PROFESSOR HUW MORRIS



AN UPDATE ON PROSPECT-UK STUDY AND WHAT IT MEANS FOR CLINICAL TRIALS

Thanks to the support of PSPA supporters, the PROSPECT-UK study began in September 2014. Today, Professor Huw Morris from UCL Queen Square Institute of Neurology shares an update on the study and its findings to date, as well as what this could mean for upcoming clinical trials.

“The PROSPECT-UK study is a multi-centre study which recruits patients with PSP & CBD across the UK, funded by PSPA. The aim is to study the causes, variation and progression of patients with PSP & CBD and our study is on track to be the largest study of its type in the world. To date we have recruited 212 PSP & CBD patients to our in-depth natural history/longitudinal studies and 440 PSP & CBD patients to our cross-sectional study.

In the natural history/longitudinal studies we carry out in depth face to face clinical assessments with blood samples, spinal fluid samples and brain

scans where possible and the cross-sectional study involves the donation of blood samples together with the completion of questionnaires looking at environmental risk factors and family history.

The last 18 months have been difficult for patients, carers and those working in the health service and things are now returning to normality. NHS clinic appointments have changed in that we now carry out telephone and video-link appointments in response to COVID-19. Similarly, we have modified the PROSPECT study assessments to allow us to carry out video link and phone assessments to

“WE HAVE DEVELOPED A RESOURCE OF ANONYMISED DATA AND SAMPLES THAT CAN BE USED BY ANY RESEARCHER EXPLORING THE BIOLOGY OF PSP OR CBD. TO DATE OVER 20 GROUPS/STUDIES HAVE ACCESSED DATA AND SAMPLES FROM THE PROSPECT-UK STUDY TO CARRY OUT RESEARCH INTO PSP & CBD.”

enable follow up of patients in the PROSPECT study and we have been able to continue recruiting patients also.

We have developed a resource of anonymised data and samples that can be used by any researcher exploring the biology of PSP or CBD. To date over 20 groups/studies have accessed data and samples from the PROSPECT-UK study to carry out research into PSP & CBD.

Our group has focussed on understanding progression in PSP & CBD using variation in genetics and biomarkers. There is a lot of variation in the rate of progression of PSP with some patients developing very marked problems early in the disease course whereas other patients may be mildly affected for 10 years or longer. We believe that understanding the biology of this variation in progression will provide new insights into the biology of PSP which will enable better designed trials.

In clinical trials we aim to see whether there is a difference in patients who are given an active study drug as compared to those who are given a placebo. It is impossible to tell whether the study drug has improved the condition without a comparator placebo group. Because of variation between patients with PSP, large placebo groups may be needed. In the recently published gosuranemab/PASSPORT treatment study in PSP the active treatment group included 321 PSP patients and the placebo group included 165. Random assignment

between the placebo and active group ensures that the two arms of the study are “balanced” - that is that they are similar in age, gender and disease severity and most importantly in predicted rate of progression. If the active treatment group are destined to progress more quickly, than the placebo group then it may be very difficult to detect a beneficial effect of the active treatment.

Using samples donated by patients in the PROSPECT-UK study in work carried out by Dr Ed Jabbari we have identified three factors that can help predict the rate of progression in PSP:

- 1) blood levels of a protein called neurofilament light (NFL)
- 2) variation in a gene cluster called TRIM11/17
- 3) variation which controls a gene called LRRK2

Using these factors to evaluate and design clinical trials could enable better matching of placebo and active treatment groups and more powerful trials which produce definite answers with smaller numbers of patients.

The association between PSP and TRIM11/17 and LRRK2 is important. We are continuing to work on understanding these links, however TRIM11/17 may be important as a “waste-disposal” mechanism in nerve cells and LRRK2 may be important for the uptake of abnormal tau protein to nerve cells leading to spread of abnormal tau protein in the brain. Potentially, therapies that address these mechanisms could slow the progression of the disease.

DR ED JABBARI



Unfortunately, the gosuranemab/PASSPORT sponsored by the Biogen pharmaceutical company and a similar large tau antibody study called ARISE studying tilavonemab sponsored by ABBVIE, did not show a benefit in slowing the progression of PSP. Both of these drugs were given by monthly infusion and it was hoped that they would bind to tau protein in the brain and slow the progression of the pathology and the disease. This was very disappointing news and patients and their families had made a huge effort to participate in these trials.

However, in these studies over 800 early stage PSP patients have been recruited at around 80 hospital sites worldwide showing that these large studies are feasible and can be carried out, even in a relatively rare condition like PSP. Further tau antibody studies are underway and a number of other studies planned to reduce the levels of tau protein are underway or planned. We hope that ultimately these studies will provide a therapy which is beneficial for PSP patients.

Looking further ahead we hope that improvements in trial design and the identification of new drug targets in the PROSPECT study will also lead to new effective therapies for PSP.

The PROSEPECT-UK study would not take place without funding from PSPA, the hard work of our collaborating research teams, and most importantly the time and effort that patients with PSP & CBD make to participate in the study with the support of their friends and family. We are very grateful for this support and hope that ultimately this will translate into real benefits for PSP & CBD patients.”



PSPA 2021 CHRISTMAS BAUBLE APPEAL

PSP/

DEDICATE A PSPA BAUBLE TO SOMEONE SPECIAL THIS CHRISTMAS

Whether you celebrate Christmas or not, it is a very special time of the year. One which is largely focused on time spent with close friends and family.

Following a diagnosis of PSP or CBD, Christmas time can be very different as families learn to adapt to changing symptoms, or experience their first festive season after losing someone close.

Each year, we launch our Christmas Bauble Appeal to offer an opportunity for our supporters to celebrate

their loved ones fighting PSP or CBD, and indeed, remember those we've lost.

Ahead of the launch this November, we wanted to share some of the personal stories behind the many baubles we receive each year, with kind donations to help fund our ongoing support services and research.



JANICE MERRITT

"Christmas is a very special time for friends and family. During the run up to the big day, I often find myself thinking of John and the good times we shared.

Married for 57 years, John and I were well matched in our love of social activities and entertaining.

We enjoyed hosting an annual Christmas Trivial Pursuit tournament with friends. An evening full of food, chat, laughter and a bit of healthy competition, of course. Men vs women.

Our world got a lot smaller though, once John was diagnosed with PSP in 2007. John's symptoms progressed quickly and soon he was unable to leave the house.

Despite this, we were supported well. By family, friends, carers, the NHS and PSPA.

In his final years, PSPA provided invaluable template letters and guidance to help me appeal when John's Continuing Healthcare Funding suddenly stopped. Thanks to this help, the funding was quickly reinstated meaning John could continue to receive the care he needed, at home, during such a vulnerable and awful time.

It is because of the support we received I donate to PSPA's Bauble Appeal each Christmas. Dedicating a

Bauble to John gives me the chance to remember all the special times we had as well as enabling me to give something back to the charity who supported us during our time of need."

ERAM OSMAN

"Each year, as Christmas approached, my mum would plan what we were going to cook each day and where we were going to go shopping for the sales!

But Christmas has not been the same since my mum was diagnosed with PSP around 2008. I can't even remember the last time we made those fun plans together.

Sadly, mum left us in Oct 2016, but I know she is with me each and every day, and supporting PSPA has now become part of my life.

Donating to the Bauble Appeal is very special and personal. It's in memory of my beautiful mum and at the same time its supporting PSPA – both who are very close to my heart".

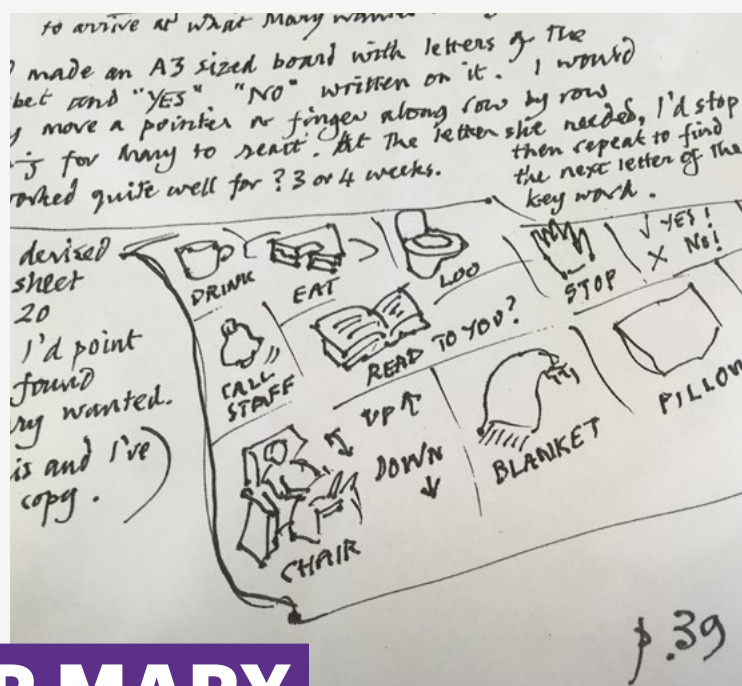
HOW YOU CAN DEDICATE A BAUBLE THIS CHRISTMAS

If you would like to dedicate a gift to someone special to help us continue supporting people living with PSP & CBD every day, simply complete the bauble you'll receive in the post.

All baubles will be hung on a special tree at PSPA head office in Milton Keynes.

You can also give a Christmas gift online at 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.

"DONATING TO THE BAUBLE APPEAL IS VERY SPECIAL AND PERSONAL. IT'S IN MEMORY OF MY BEAUTIFUL MUM AND AT THE SAME TIME ITS SUPPORTING PSPA – BOTH WHO ARE VERY CLOSE TO MY HEART".



CARING FOR MARY

Caring for a loved one can be extremely rewarding. It can also be a challenge as you get to grips with PSP or CBD, how the symptoms progress and learn how best to support your family member. Here Michael Riggs shares his highs and lows in a diary he kept whilst caring for his wife, Mary.

An introduction

So many people cared so well for Mary, and for me too. So many to thank – I hope you will recognise our gratitude, gentle readers. Looking back, I can see that Mary's CBD started about 2010. Early symptoms were just a puzzle; hence my log begins in 2013.

This is a patchy record. It stops and starts, probably reflecting my own capacity to deal with the intensity of challenges as they cropped up. Mary was a very dear wife throughout our 52 years of marriage. Anyhow, here's the log, warts and all.

September 2013: Mary is anxious about the kettle although we have it on a tilting stand. She does not feel competent using this when the kettle has boiled.

Mary sat down to play with our granddaughter Martha (now two years old) and tipped over backwards. Tears of sheer frustration at not being able to sit and play with her followed. During the unfolding of this disease, it's the only time that she has wept.

In the bookshop I asked whether they had any books to help people to learn to write left-handed. Apologetically they proffered a book suitable for children. I nearly wept. I thought of Mary's once dexterous fingers skipping over the piano keyboard, producing the intricacies of Bach and Chopin. Such lovely hands...

Mary's irregular sleeping patterns at night continue. She often takes off to the spare room to avoid disturbing me.

October 2013: Mary is very cheered by a telephone call from PSPA. She was also pleased to receive today's mail from the charity, an information pack which is clear, informative and understanding of CBD.

No physio, OT or speech therapy has yet materialised, despite our emails to the GP. A further telephone call with PSPA, who is sending an information pack to our GP. Mary is pleased about this. Me too! They suggested we apply for a blue badge – Success!

As Mary picked up a tomato with her faulty hand, she inadvertently crushed it, squirting pips and juice at me. A laugh, at least.

November 2013: The NHS physio visited yesterday and has given Mary some exercises; I shall have to help with some of these. (They might do me some good too!)

Spent the weekend with Tom and Hels. Martha was a delight and Mary useful in entertaining her with books and conversation. A great boost that confirms we really should move as soon as our bungalow can be adapted. I met Jim from Somerset Care and Repair and we discussed access. The bath has been removed and the wet room completed. Mary is very pleased.

An enjoyable jaunt to Birmingham with Martyn. Meanwhile thinking of Mary at home toying with cold chicken, pre-cut-up for easy eating. I hesitate to tell her I had a good time: it's a very unequal distribution of pleasures.

December 2013: We are getting through more wine than we used to. I think I must remind myself not to head for the bar if I am feeling a bit down. I imagine that booze could become a problem for the undisciplined carer.

Somehow backache recurred at force seven. I simply could not bend low enough to get a roasting tray from under the oven, but Mary was able to do this! It's a salutary reminder of the need for the carer to keep fit.

Drinks at 7.15pm with friends. It was a pleasant evening of quiet chat with sympathetic people. Very good to have Mary participating.

January 2014: At present we are capable of getting along without too much stress. Mary continues to manage some tasks. I could do them in a fraction of the time, but I guess it's important that she continues to do what she can.

February 2014: Backache, much pain, I'm stuck in bed. Mary had another fall, fortunately missing the rockery. Have we reached a stage where she must not be left alone? I think we have. Buy an alarm pendant? Carry her mobile phone?

A surreal scene. Can I prepare brussels sprouts whilst lying prone in bed with backache? Mary

has lost the dexterity to manage these sous-chef tasks. Brussels in bed, we have a laugh...

22 April is offered,

So I will just have to stick it out.



June 2014: Little to report, other than further small steps on the downward path. Many familiar operations are taking longer: dressing particularly.

March 2015: This lifting Mary around is giving gyp to my shoulder.

Mary is depressed and doesn't want to go for the planned respite 1 to 3 April. I feel dreadful about this because respite from CBD is mine, not hers. Everyone tells me I need a break and that carers need to care for themselves in order to do an effective job. I think I am managing all right, but I'm racked with guilt when I leave, thinking of her while I'm away. I'm inhibited about indulging myself while she is so stuck.

April 2015: We are investigating live-in care and Bluebird's Tracey is coming to assess. My blood pressure is low – is that why I feel lethargic? Yet another fall. Picking her up is a struggle and I should not do it alone. It seems there is no alternative as I am reluctant to call the paramedics.

June 2015: Communication is worsening, another day of tears and depression which I seem unable to influence.

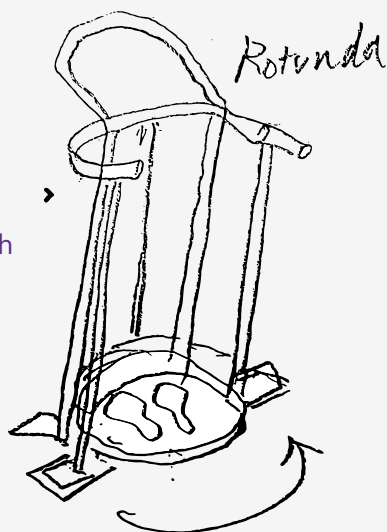
Consultant psychiatrist visits, medication started. I am trying to sort out a powered chair.

July 2016: Up just after midnight, again 2.30am, 7.30am, 8.15am. This lifting is getting difficult – bloody backache and hernia now.

August 2016: The children think I am doing too much and need more of my own life. I now feed Mary with a spoon, as she can hardly manage a cup or a glass. I'm using the rotunda a lot because my shoulder hurts again. Bluebird insists on two carers at a time now: this doubles the cost.

October 2016:

This week, Mary and I completed an Advance Decision form. Speech therapist Alison visited with drink thickeners. Has Mary a tummy bug? Or incontinence? Accident at 7.20am that had me mega-retching.



February 2017: Following the BCS team visit we started to use MyGaze talker. It's extremely fiddly.

March 2017: MY HERNIA – it's now urgent but not an emergency. NHS will take weeks for a referral, or I could be referred to a private clinic. Do I fund care cost whilst waiting weeks to see a specialist and wait for an operation? Or go private? A no-brainer decision was to go private – how money talks! Consultation next day, operation in seven days, in and out same day. Family and Charlotte rallying round.

THE MATHS... (Pessimistic scenario) CARE COSTS. NHS.

(A) 1	£250/day for 21 days	2	£250/day for 16 weeks
	$\frac{5000}{250}$		$\frac{2500}{1500}$
	£5250		£4,000
	+		= £9,250

(B) Going Private... c. £2,000 (+ a few %)



It's a no-brainer to decide to go private!

April 2017: Today, Mary is in a care home. I have dreaded taking her from our home. But she has been composed and I think, having decided what to do, has mentally prepared or resigned herself to this move. So how does she feel tonight, I wonder? Is she missing me as I miss her presence in this bedroom as I write this in bed? The house is so quiet!

June 2017: Mary has coped with a string of visitors. They thought Mary was just about managing but conversation was very difficult.

September 2017: Mary's eye and hand coordination have gradually declined. MyGaze has become impossible. A neurology nurse visited to confirm what I had discussed with the SLT previously, particularly about PEG and end of life.

Mary took a cognition test and gave 'excellent' results as I expected. Some of the questions I felt were ill thought out which niggled me. For example, musicians such as Mary do read music as well as listen.

December 2017: We took Martha and unopened Christmas presents to be opened chez Mary, but I think she found having all five of there overwhelming. Anna and I remained to feed Mary lunch and we then went home to cook dinner for ourselves. I was not in the mood but glad to occupy myself and keep my mind off Mary's plight.

March 2018: With Mary's decline I spoke to our GP surgery to look at the possibility of gaining CHC funding. I am told the care home should help arrange the needed assessment and application. I have asked them to start the application as a matter of urgency. They seem empathetic that Mary needs the funding now.

June 2018: Mary is now eating pureed food since she choked on shepherd's pie. She still eats fairly well despite her declining condition and although she is losing a little weight she seems remarkably physically fit.

We met with the care home to confirm end of life wishes. No interventions, including antibiotics. Just in case meds will now be available. I told Gill that Mary's brain donation had been arranged and details should all be on file.

Michael's wife Mary sadly passed away from CBD in October 2018. We thank Michael and his family for sharing their experience of caring for Mary and how CBD impacts the whole family.



TRUCK RUN IN MEMORY OF MICHAEL

After Michael Wilde passed away from PSP earlier this year, his nephew Ed set about organising an event in his memory which would not only raise awareness of the condition but also raised funds for research. Here, Michael's wife Rebecca shares how the event went.

"The Truck Run was originally planned as a birthday surprise for Michael by his nephew Ed Wilde, but Michael unfortunately passed away from PSP before Ed had chance to plan for the run.

After a small "corona" funeral for Michael, Ed was adamant that the truck run should still go ahead in Michael's memory. So, on 17 July in glorious sunshine we all gathered at Halls Cattle Market in Shrewsbury, Shropshire. Dianne who organises and runs our PSPA Local Group came with her grandson James and set

up a PSP information hub! Everyone had literature and balloons and donations were plentiful.

In total we had 59 lorries and 30 other vehicles of all sizes taking part in the truck run, this included American cars, sports cars, vans, Land Rovers - anything went! It was fantastic.

After gathering earlier in the morning, at 10.30am we went in convoy from Shrewsbury to Cannock truck stop with horns blowing! It was

an unbelievable sight. Ed had also arranged for photographers along the route who captured the essence of the day.

The turnout of the vehicles was spectacular. As well as being great fun, the day in total raised just over £7,000 for research into PSP. Michael had a long, horrid battle with this disease. He had participated in research projects into PSP being run at John Radcliffe hospital. It was his wish, that

upon his death, his brain would be donated to the London Neurodegenerative Diseases Brain Bank to enable them to carry out invaluable research.

Hopefully we have managed to raise the profile of PSP with the truck run and raised much needed funds for research.

Special thanks to Ed for his hard work in organising this wonderful and poignant day."





DAILY LIVING - HOW THE OCCUPATIONAL THERAPIST CAN HELP

The progression of PSP & CBD affects everyone differently, unfortunately, there isn't a one size fits all list of useful or essential equipment. Symptoms occur and progress differently; this is why it is so important to be linked to an Occupational Therapist (OT) as soon as possible following diagnosis. Julie Cummins is an OT who works within the social services' early intervention team in Wigan, she has also worked within the NHS as an OT, her late father lived with a diagnosis of PSP. This wealth of experience gives Julie a unique insight into the needs of those living with PSP & CBD, following on from speaking to our Newly Diagnosed Group, Julie shares some hints and tips regarding daily living, access to and suggestions of useful equipment.

JULIE'S TOP TIP - It can take some time for people to move along a waiting list for an assessment, so it is important that you are referred to an OT and Physio as soon as possible.

MOBILITY

Assessment by an OT or Physio will avoid you purchasing and using equipment which isn't suitable. Height, weight, dexterity, and gait are all factors to consider- early on a walking stick

or four-wheel walker may be helpful. As mobility deteriorates, wheeled Zimmer frames provide more support. Kitchen trolleys can be helpful and enable the user to maintain independence as drinks, snacks and other items can be transported on the tray. Consider a wheelchair for outside and those long walks to and from appointments, these can be provided by wheelchair services and in some areas can be loaned, assessment is essential.

ACCESS

Grab rails fitted at the correct height and position can be helpful, especially on doorways and the bathroom. Early assessments will involve looking to the future. Access in and out of the house and stairs and steps as PSP or CBD progresses and mobility reduces - alterations may be required and can be made such as additional steps, rails, and ramps. Thinking about this ahead of time means you are prepared should changes happen unexpectedly.

SEATING

Anything that is low, can become difficult to manage, chair raisers are a simple way to help with this, although the feet of your sofa or chair will need to be suitable. Armchairs are better than sofas because there are two arms to use to push yourself up. Riser recliner chairs are good if someone is really struggling with the standing/sitting movement. Often these do need to be purchased privately, Julie suggests it's always a good idea to speak to your OT first, they may supply one, even as a loan to be sure it works for you before purchasing. You may also be able to hire one rather than buy outright.

BEDROOM

If your bed is low this may be problematic, bed raisers can be provided to lift the bed higher. Raising the head of the bed, either with pillows or a backrest will provide support when moving from lie to sit on the edge of your bed. Bed levers can be fitted to most single and double beds, they provide support and stability when transferring on/off the bed.

Commode for the side of your bed if struggling to mobilise to toilet at night

JULIE'S TOP TIP – Glide and Slide sheets can aid turning in bed

BATHROOM

Toilet raisers are really good, they fit to a standard toilet bowl and come in heights 2", 4" and 6". Other members of the household need to be considered so they can still access the toilet comfortably also. Depending on space around the toilet a free-standing toilet frame could be fitted - this is a frame with arms that sits around the toilet and makes it easier to sit down and push up from. If space is limited grab rails could be fitted at the side of the toilet. A Glideabout commode, which is a commode on wheels with breaks can be moved around the home if someone is really struggling with mobility.

A wet room or completely level access shower is the ideal as there are no shower basins/cubicles to negotiate, If there is a wet room Julie advises a shower chair. Speak to your OT about the possibility of this against your present bathroom space. Generally, it will become too difficult to get down into a bath so a battery-operated bath lift that lowers and raises the person or a shower board over the bath to sit on is good.

JULIE'S TOP TIP - a long handled shower sponge

MEALTIMES

Things to consider making eating and drinking easier. Plate guards that make it easier to scoop up food, you can buy the plates with raised sides or get a guard that clips on. Adaptive cutlery - bigger handles to grip onto. Cups with two handles or a beaker depending on speech and swallow, your Speech and Language Therapist may be able to advise on adapted crockery and cutlery as well.

Kettle tipper to support the weight of the kettle, One cup kettles like the Breville Hot Cup are also helpful. Millie-Mova chair aid - this is one of the best things to help someone to be able to sit at the table and eat meals.

JULIE'S TOP TIP - Raise your plate on some thick books and try a bright coloured plate, a blue or red rim can help as it makes the plate easier to see. You could also try a pair of prism glasses which can be provided by PSPA helpline.

If you have any questions about something you have read in this article or would like more information about how and where to access aids to make life easier please contact the PSPA helpline- **0300 0110 122**
helpline@pspassociation.org.uk

If you want to check out some of the items mentioned in the article, to see what they look like online try, NRS Complete care shop - **www.completecareshop.co.uk** Ableworld- **www.ableworld.co.uk** Aids for mobility - **www.aids4mobility.co.uk**

THANK YOU #TEAMPSPA

Despite the restrictions continuing into 2021 #TeamPSPA have been busy fundraising and setting themselves challenges locally, across the UK. Here are just a few of the challenges and events people have held for us throughout the year. Thank you!



JENNIFER KEAVENEY TOOK ON A POWER OF TEN CHALLENGE, BAKING TEN CAKES TO SELL FOR PSPA AND RAISING £85!



ELLIE CHARLES RAN A VIRTUAL ROYAL PARKS HALF MARATHON IN APRIL, RAISING MORE THAN £5,000!



MATT MOREY RAISED £4,364 BY WALKING 130 MILES LOCALLY IN HIS HOME TOWN AS PART OF HIS #WALKINGFORDAVE CHALLENGE.



ERAM OSMAN KINDLY DONATES 25% OF SALES FROM HER HAND MADE CARDS BUSINESS TO PSPA.



CHRISTINE HARRISON, WHO IS LIVING WITH PSP, RAISED MORE THAN £1,300 AFTER SHE TOOK ON THE CAPTAIN TOM 100 HAND CYCLING CHALLENGE FOR PSPA.



LOUISE BENGOUGH AND HER FAMILY RAISED £425 FOR PSPA VIA A TRIBUTE FUND THEY SET UP IN MEMORY OF LOUISE'S DAD, JOHN.



#TEAMMALC CONTINUED THEIR FUNDRAISING EFFORTS, WITH THEIR FIRST FACE-TO-FACE EVENT THIS SUMMER. THE PLANT SALE RAISED £1,300.



WILTSHIRE FARM FOODS

As symptoms progress, people living with PSP & CBD may begin to have difficulties swallowing. This can affect your ability to enjoy mealtimes with your family as well as your favourite foods.

Soft foods and puréed meals can be a way to ensure people living with PSP & CBD can still enjoy your favourite flavours, whilst reducing the risk of coughing and choking on foods.

Josephine Bailey, 50, was recommended Wiltshire Farm Foods by her SLT:

“I started ordering in 2019 as they have meals with different levels to suit various swallowing needs. Initially I enjoyed level five (Minced & Moist) meals, however, as my swallowing issues have worsened, I have been able to switch to level four (Puréed) meals. The meals look and taste great and were a welcome relief from home-blended food.”

“My family was puréeing everything with a hand-held blender, which wasn’t working very well, and

everything resembled mush. Cooking and then puréeing the food was also really time consuming and it was often cold by the time they had mashed it into the correct consistency.”

For Josephine, the Wiltshire Farm Foods home delivery service took the stress out of mealtimes as it meant there was no pressure on her relatives to cook separate meals or hand blend foods for her, adding to the anxiety around appropriate food texture whilst ensuring essential nutrients were still included:

“When I started ordering meals, we were all adapting to changes in my progressing symptoms so we really appreciated the convenience of having them delivered. This meant my family could just pop a meal in the microwave straight from the freezer, making life so much easier. The Minced

JOSEPHINE BAILEY



““WHEN I STARTED ORDERING MEALS, WE WERE ALL ADAPTING TO CHANGES IN MY PROGRESSING SYMPTOMS SO WE REALLY APPRECIATED THE CONVENIENCE OF HAVING THEM DELIVERED.”

Creamy Chicken Pie and Puréed Cheese Omelette are both firm favourites.”

But it's not just the meals that Josephine appreciates, it's the good old-fashioned service too; something which the Wiltshire Farm Foods team prides itself on, in this modern age of automated phone systems and online ordering.

“The team are such a friendly bunch and every time I call to place my order, I can have a chat and a laugh which is lovely. I especially appreciated it when having to shield during the pandemic given how isolated I felt at times. Having a cheerful voice at the end of the phone really lifted my spirits.”

Josephine's driver, Dan, is never too busy to stop for a chat and it's this personal touch which, she says, sets Wiltshire Farm Foods apart from other delivery companies:

“He always has a smile on his face and isn't in a hurry to rush on to the next delivery, so we can

have a bit of a chat. If I ask, he'll even put the meals straight into my freezer, which is not something your average home delivery service provides.”

For more information visit: wff.link/PSPA



HERE FOR YOU

Our Helpline Care Navigators are here to support people living with and affected by PSP & CBD. Each Helpline Care Navigator has a designated area (see map) where they can provide proactive support, including:

- Information on all aspects of living with PSP & CBD, such as symptom management, benefits and entitlements and everyday living.
- Emotional and practical support.
- Contact details for local support, which may include a Local Group.
- Information about how PSPA can support you.
- Information about health and social care and how to access these services.
- Signposting to other sources of information.
- Referral for non-means tested benefits applications via Department of Work and Pensions (DWP) home visiting service.
- Supporting evidence about PSP & CBD for Blue Badge applications and Continuing Healthcare applications.
- Provide specific information written for health and social care professionals and access to Education Volunteers.

Our helpline and information service is available Monday to Friday 9am-9pm.

Tel: **0300 0110 122** or email **helpline@pspassociation.org.uk**

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