**RAISING AWARENESS IN YOUR LOCAL MEDIA  
A guide for volunteers**

As fairly unknown conditions, we know our volunteers are keen to do whatever they can to help raise awareness of PSP & CBD.

You have a wealth of knowledge and information you can share with your local media from your own experiences, to help others and spread the word amongst your community.

To ensure that together, we can create the greatest impact possible, helping to improve diagnosis and care for the 10,000 people living with the conditions, we’ve pulled together some useful information, tips and templates to help your voice be heard in local newspaper articles and radio interviews.

Keep reading to learn more about how you can support our awareness raising in your local media.

Inside you will find…

* Core messaging about PSPA and our goals
* Key facts and figures
* Media dos and don’ts
* Press release templates
* Logos and images.

If you need any support with your media or awareness activities, please contact PSPA’s Communications Team:

[communications@pspassociation.org.uk](mailto:communications@pspassociation.org.uk)   
01327 356135

**PSPA’S CORE MESSAGING**

Use this information to tell people about who we are and what we do.

**OUR AIM:**

To create a better future for everyone affected by PSP & CBD

**OUR GOALS:**

1. SUPPORT AND INFORMATION - Enabling people to live the best life possible
2. RESEARCH ANDAWARENESS RAISING - Improving quality of life
3. INVOLVEMENT - Putting people living with PSP & CBD at the heart

**WHO WE ARE:**

PSPA is the UK’s leading centre of knowledge, experiences and support for people living with PSP or CBD and their families.

Our people have experience and knowledge to help individuals understand the conditions and support available to them.

**WHAT WE DO:**

We work to ensure the 10,000 people with PSP or CBD receive support and care that is co-ordinated, has continuity and is compassionate.

**WHY WE EXIST:**

* Our work is important because people with PSP & CBD do not receive timely diagnoses or adequate support and care.
* For one in three people, it takes over one year to be referred to a neurologist by their GP
* 60% of people living with PSP or CBD initially receive a misdiagnosis.

**OUR CALL TO ACTION:**

Together we can improve diagnosis for the 10,000 people living with PSP & CBD, saving time, resources and helping patients get the care they need faster.

**KEY FACTS AND FIGURES**

Here are some key facts and figures to help support your awareness raising activities.

* PSP & CBD are neurodegenerative conditions
* Key symptoms include

PSP: Balance problems, backwards falls, a fixed gaze, apathy, speech and swallowing problems

CBD: One side affected, alien limb, apathy, speech and swallowing problems, problems with cognition

* The conditions affect both men and women
* Symptoms of the conditions can begin as early as 40 years old; the average age is over 60 years old
* The conditions are caused by an accumulation of abnormal tau protein, resulting in the premature death of neurons in the brain
* PSP & CBD affect approximately 5 people in every 100,000 although research leads us to believe the figure could be much higher
* There are currently no treatments to slow the progression of the conditions, and no cure.

**MEDIA DOS AND DONTS**

Sharing your experience of PSP or CBD, why you volunteer and about any events you hold, is a great way to raise awareness in your area.

Below are some useful tips to help you plan and execute stories for your local newspaper, magazine or radio station.

**DO**

* **Be proud** of your volunteering role and the difference you make by sharing your achievements
* **Plan** what story you want to tell and why
* **Pick a theme**: whether it is to flag up PSP & CBD symptoms to improve diagnosis, promote support available, encourage people to attend an event you are hosting or highlight education sessions you can host
* **Provide insight into how daily life changes** as well as initial symptoms
* **Sign post PSPA support and information** by sharing how the charity has helped you and your family
* **Give a call to action**: this could be looking up the charity, attending a support group or sharing a Red Flag poster
* **Work with PSPA** to tie your story into central awareness activities
* **Provide contact details** of PSPA or the event/education session organiser
* **Include photos** documenting your story
* **Reference PSPA** for any central images you use in your coverage
* Utilise the **information and figures** provided in this pack to help shape your media pitch
* Adapt our **template press releases** to ensure we are all sharing the same message and information about PSP & CBD
* **Spell check** and get someone to proofread your story before you circulate it
* Let our Communications Team know about any **media coverage you secure**
* **Ask PSPA for help** if you need guidance ahead of writing a release or taking part in an interview.

**DON’T**

* **Rush any media coverage** you want to gain; take the time to plan what story you want to tell, why and how
* **Try to cover too much** in one piece, if you have lots planned, think about what is important to share and when
* **Mix messages** from across different campaigns or organisations – this could be confusing and dilute the impact the media coverage can have
* **Use any images or quotes you don’t have permission** for, always gain consent first and reference the relevant organisations and people
* **Publicly criticise named healthcare professionals** if you have been unhappy with the service they provided, utilise complaint processes to feedback
* **Refer to your volunteering role out of context**. For example, PSPA has Support Groups and Education Volunteers, but not regional branches or offices
* **Speak on behalf of the charity** – focus on your own experiences and thoughts
* Be too **upset if don’t get a response**. You can always chase in a few days’ time or find another way to have you voice heard.

**PRESS RELEASE TEMPLATES**

1. **VOLUNTEERING TO SUPPORT FAMILIES IN [ADD IN TOWN/CITY]**

A [ADD IN TOWN/CITY] local has signed up to volunteer to help families affected by two rare brain diseases.

[ADD IN NAME], [ADD IN AGE], from [ADD IN SPECIFIC LOCATION] signed up to be a volunteer for UK charity PSPA in [ADD IN DATE].

[ADD IN NAME] joined the charity as a [ADD IN VOLUNTEER TITLE] to help provide support, information and raise awareness of Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD).

PSP & CBD are rare neurodegenerative conditions caused by the loss of nerve cells in certain parts of the brain. Over time this causes problems with balance, speech, vision, swallowing and mobility. Currently there is no treatment and no cure.

There are up to 10,000 people living with the conditions in the UK.

[ADD IN NAME] was inspired to volunteer for the charity after [ADD IN CONNECTION TO PSP & CBD – i.e. dad was diagnosed with PSP in 2020).

During their [PSP/CBD] experience, [ADD IN NAME] found very few people had heard of the conditions before, including some of the healthcare professionals they encountered.

[ADD IN NAME] said: “[Add in quote detailing first symptoms and diagnosis]

“[CONTINUE WITH EXPERIENCE OF GETTING SUPPORT/AWARENESS AMOUNGST YOUR COMMUNITY AND WITH HEALTHCARE PROFESSIONALS]

“[ADD IN WHY YOU WANTED TO VOLUNTEER FOR PSPA AND WHAT YOU HOPE TO ACHIEVE.]”

PSPA currently is supported by more than 200 loyal volunteers.

The volunteers help to deliver both central and community-based services such as the Helpline, Support Groups, the Link Volunteer Service and PSP & CBD Education Sessions. For more information about PSPA and the difference volunteers can make, please visit [www.pspassociation.org.uk](http://www.pspassociation.org.uk)

1. **PSPA SUPPORT GROUP HELPING FAMILIES IN [ADD IN TOWN/CITY]**A support group for people living with two rare brain conditions is launching/being held in [ADD IN TOWN/CITY] ON [ADD IN DATE OR FREQUENCY].

The Support Group will be held [ADD VENUE NAME, AREA, POSTCODE] and aims to support people living with Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD) and their families.

PSP & CBD are rare neurodegenerative conditions which over time, cause problems with balance, movement, vision, speech and swallowing. The two conditions affect approximately 10,000 people in the UK. Currently there are no treatments, and no cure.

[ADD IN YOUR NAME] is the volunteer Support Group Coordinator who is helping UK charity PSPA to organise the group meetings, which takes place once a month/[UPDATE FREQUENCY]. The next meeting is taking place AT [ADD IN TIME] on [ADD IN DATE].

[ADD IN YOUR NAME], has experience of the rare conditions after [ADD IN DETAILS OF YOUR CONNECTION TO PSP & CBD].

[ADD IN YOUR NAME] said: “[There is very little public awareness of the devastating effect PSP & CBD can have on people affected by them and their need for support.

“[ADD IN QUOTE ABOUT YOUR EXPERIENCE OF PSP & CBD AND WHY YOU CHOSE TO SET UP A GROUP IN THE AREA]”.

Anyone who would like to join the PSPA [ADD AREA NAME] Support Group Meetings, can email volunteering@pspassociation.org.uk for more information.

For venue details and meeting dates, please visit [www.pspassociation.org.uk](http://www.pspassociation.org.uk)

1. **SPOTTING THE RED FLAGS OF RARE BRAIN DISEASE IN [ADD IN TOWN/CITY]**This week [ADD IN NAME OF COMMUNITY GROUP OR CARE HOME] learned how to spot important ‘Red Flags’ for two rare brain diseases.

During an education session led by UK charity PSPA on [ADD IN DATE] the [HOME/GROUP] found out how to spot the signs and symptoms of Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD).

PSP & CBD are rare neurodegenerative conditions which are often misdiagnosed as Parkinson’s disease, depression or stroke.

The key symptoms the group was told to look out for include:

* PSP – backwards falls, eye changes, speech becoming slower or softer
* CBD – weakness in one side of the body, an alien limb, cognition changes

The PSP & CBD education session was delivered by PSPA Education Volunteer [ADD IN YOUR NAME] to a group of [ADD IN NUMBER OF ATTENDEES] locals with the aim of making more people aware of the conditions and how they can get support.

As part of the session [ADD IN YOUR NAME], shared details of her own experience of PSP & CBD, something that inspired [HER/HIM] to volunteer.

[ADD IN NAME] said: “[ADD IN QUOTE DETAILING EXPERIENCE OF DIAGNOSIS AND AWARENESS LEVELS IN COMMUNITY AND WITH HEALTHCARE PROFESSIONAL.] “[ADD IN FURTHER DETAILS ABOUT WHEN YOU BECAME A PSPA VOLUNTEER AND WHAT YOU HOPE TO ACHIEVE]”

PSP & CBD education session are available across the UK, in-person or online. To book a session for your community group, or your local care home, please email [volunteer@pspassociation.org.uk](mailto:volunteer@pspassociation.org.uk). For more information about PSP & CBD, please visit [www.pspassociation.org.uk](http://www.pspassociation.org.uk)

**LOGOS AND IMAGES**

Please utilise the below logos and images in any promotion or media you gain.

**PSPA LOGOS**Please use the PSPA logo in its original form. Do not crop, adapt or change the logo.

A purple letters on a white background

Description automatically generated

A purple and orange text

Description automatically generated A purple and orange text

Description automatically generated

**IMAGES**

When using the images below, please reference copy right to PSPA.

A person sitting at a table with a person in a blue shirt

Description automatically generated Two men in a room

Description automatically generated

 

A person and person walking out of a building

Description automatically generated A group of women wearing matching purple shirts

Description automatically generated

A person hugging a person

Description automatically generated A person in a wheelchair

Description automatically generated

Original files of the logos and images can be found [**here**](https://pspassociation476.sharepoint.com/:f:/g/ErExsm003Z1Crf0bwWvnkVwBouCZIkmrmt3HdE6zddpnTA?e=jhZIZ7).