

## IF YOU NEED FURTHER INFORMATION

If you need more information or support, or would like to order our publications, contact our helpline.

PSPA Helpline 0300 0110 122

[helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

[info@pspassociation.org.uk](mailto:info@pspassociation.org.uk)

## PSP/

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

Telephone 01327 322410

Registered charity numbers:  
England and Wales 1037087, Scotland SCO41199

# PSP/

## LIVING WITH PROGRESSIVE SUPRANUCLEAR PALSY

PSP: what to expect from your care



CARE **STARTS  
HERE**

PSPA is the only charity in the UK supporting Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD), which is sometimes known as Corticobasal Syndrome (CBS).

For more information about us, visit [www.pspassociation.org.uk](http://www.pspassociation.org.uk)

You can use this guide to open discussions about your care with health and social care professionals and providers. This may help you access suitable support at the right time. The pages that follow highlight recommendations for good care, but you are unlikely to need all of these at once.

Use the questions provided to help you discuss your needs as they arise and plan ahead for future care.

**This guide was supported by unrestricted educational grant from UCB Pharma Ltd**

**FOLLOWING**

**DIAGNOSIS**

### **HAVE YOU BEEN:**

- Offered a follow-up appointment with a neurologist?
- Offered written information including access to supporting organisations?
- Offered a care plan and been involved in its development?

## ORGANISING

### YOUR CARE

#### HAVE YOU BEEN:

- Given the details of a named key worker/point of contact?
- Offered regular reviews of your care and medication, through your multidisciplinary team?
- Offered a referral for prompt management of symptoms by a specialist palliative care team?

## MOVEMENT

### AND BALANCE

#### HAVE YOU BEEN:

- Referred to a physiotherapist and/or an occupational therapist to help maximise your independence?
- Assessed and treated for risk factors related to your current and future needs e.g. osteoporosis, falls, visual disturbance?
- Assessed for equipment, adaptations and/or safety measures to meet your current and future needs?

## VISION AND OTHER

## SENSORY CHANGES

### HAVE YOU BEEN:

- Referred to an ophthalmologist for assessment and possible prescription of specialist glasses?
- Referred for an assessment of your home environment to reduce any hazards?
- Given an opportunity to ensure any changes in vision are not affecting your communication?

## COMMUNICATION

## AND SPEECH

### HAVE YOU BEEN:

- Assessed by a speech and language therapist for your communication needs, or reviewed if your needs have changed?
- Referred for further assessment if you need communication aids?
- Given help to ensure any communication aids work well with other assistive equipment that you may use?

## SWALLOWING

## AND NUTRITION

### HAVE YOU BEEN:

- Assessed and offered support/treatment if you have saliva problems?
- Assessed for any swallowing, eating and drinking difficulties or associated issues such as chest infections or breathlessness?
- Given the opportunity to discuss alternative ways to receive nutrition, such as tube feeding?
- Given the opportunity to discuss and plan ahead for your future needs and wishes?

## BLADDER AND

## BOWEL

### HAVE YOU BEEN:

- Given advice from a dietitian on diet and fluid intake?
- Given advice on bowel care by the community nursing team?
- Assessed by the continence nurse and given access to appropriate products?
- Given a medication review if continence is a problem?

## THINKING AND

## BEHAVIOUR

### HAVE YOU BEEN:

- Asked about any changes to your thinking or behaviour?
- Referred for a formal assessment if needed?
- Informed about access to emotional support for you and your carers?
- Given the opportunity to express your wishes in your care plan?

## FATIGUE

## AND SLEEP

### HAVE YOU BEEN:

- Referred to an occupational therapist for advice on fatigue management?
- Assessed and given advice if sleeping patterns are a problem?
- Given a medication review if sleeping is difficult?

## PAIN

## MANAGEMENT

### HAVE YOU BEEN:

- Assessed by a physiotherapist if limb stiffness is a problem?
- Advised how to communicate that you have pain if your speech is affected?
- Referred to the specialist palliative care team to help with complex pain symptoms?

## PLANNING

## AHEAD

### HAVE YOU BEEN:

- Offered an early opportunity to discuss future care concerns about your condition and end of life, if wished?
- Given support and advice about planning ahead for future care?
- Given prompt access to specialist palliative care services, if needed?

## WHAT CAN I DO IF MY

## NEEDS ARE NOT MET?

If you do not receive the care or treatment you need, or have any problems, discuss this first with the relevant health or social care professional, or care provider.

If this does not improve the situation, make a formal complaint or appeal to the service involved. They should be able to provide information or advise how to do this.

## IF YOU NEED FURTHER

## HELP OR SUPPORT

PSPA resources for people affected by PSP: <https://tinyurl.com/yxtevr4s>

PSPA resources on benefits: <https://tinyurl.com/yxaszfbj>

PSPA resources on Continuing Healthcare Assessments (CHC): <https://tinyurl.com/yxmq8yhr>

PSPA resources on other sources of funding: <https://tinyurl.com/y4wapz39>

PSPA resources for Health and Social Care Professionals: <http://tiny.cc/y1td6y>

PSPA Research opportunities: <http://tiny.cc/rmrd6y>