



# A Guide to PSP and CBD for General Practitioners and the Primary Healthcare Team

---

## Introduction

This booklet is published by the PSP Association (PSPA). It is part of a series of publications for health and social care professionals, to help them support people who are living with Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD). Providing the care and support required for someone living with these conditions can be one of the most challenging experiences faced by a General Practitioner (GP) who may only come across these conditions once or twice in their professional lifetime.

The purpose of this booklet is to provide GPs and the primary healthcare team with information about PSP and CBD with particular focus on:

- Diagnosis and early referral
- Improving the quality of life of patients by increasing the GP's awareness of the type of problems/symptoms encountered and effective symptom management
- Timely involvement of the multidisciplinary team (MDT), including the palliative care service, to support and assist people living with the condition, their families and carers.

Decisions regarding management of symptoms should be made by the patient, with guidance and support from their neurologist or movement disorder specialist, GP and other members of the MDT.

The ultimate goal is to provide an individual, personally tailored approach to care that is coordinated with access to appropriate information and advice to help the patient to make informed choices.

PSPA work in the interests of people living with PSP and CBD and often uses PSP as shorthand for both. This guide refers to the conditions separately where there are distinct differences, as appropriate.

This booklet is intended as a guide only and the information is published in good faith. It is not a substitute for the advice and experience of the consultant or other medical experts involved in the provision of care.

---

## Contents

|  |    |
|--|----|
| Introduction                                 | 2  |
| Contents                                     | 3  |
| Presentation – PSP                           | 4  |
| Presentation – CBD                           | 6  |
| Aetiology and treatment                      | 7  |
| Red Flags                                    | 8  |
| The management of PSP and CBD                | 9  |
| Movement and mobility                        | 11 |
| Pain   | 13 |
| Speech and Communication                     | 14 |
| Dysphagia                                    | 15 |
| Bladder and bowel                            | 17 |
| Vision                                       | 18 |
| Cognition                                    | 19 |
| Palliative care                              | 20 |
| Support for families and carers              | 22 |
| Psychological support                        | 24 |
| Research                                     | 25 |
| Brain donation                               | 26 |
| Further information from the PSP Association | 27 |
| The PSP Association (PSPA)                   | 28 |
| Acknowledgements                             | 30 |
| References                                   | 30 |
| We welcome your views                        | 30 |

---

## Presentation – PSP

### DESCRIPTION

Progressive Supranuclear Palsy, previously known as Steele–Richardson–Olszewski Syndrome, is a neurodegenerative condition, classified as a movement disorder. It is defined by the accumulation of tau protein, which forms neurofibrillary tangles in the brain causing premature death of the neurons. The principal areas of the brain affected are:

- The basal ganglia (particularly the subthalamic nucleus, substantia nigra and globus pallidus)
- The brain stem
- The cerebral cortex
- The dentate nucleus of the cerebellum.

---

Early symptoms may include the inability to look up or down.

---

### ONSET

Early symptoms may include:

- The inability to look up or down (known as a supranuclear vertical gaze palsy)
- Initially vertical eye movements may be slowed
- Parkinsonism (‘extrapyramidal symptoms’ of slowness and stiffness)
- Often symmetrical and predominant stiffness in the neck
- Falls – often backwards
- Striking facial appearance often with frontalis overactivity (‘startled expression’) and reduced blink rate
- Cognitive dysfunction.

### EPIDEMIOLOGY

- Unlikely to occur below the age of 40 – average age of onset is 62
- Median interval between onset and diagnosis is three years
- Slight male predominance in most studies.

### INCIDENCE AND PREVALENCE

Prevalence: 6.4 per 100,000. – This constitutes around 5% of parkinsonian patients seen in the movement disorder clinic.

---

---

A useful acronym to aid differentiation between Parkinson's disease and PSP – **FIGS**

---

## DIFFERENTIAL DIAGNOSIS

To date, definitive diagnosis of PSP can only be made by post mortem examination of the brain. Specialists can make the diagnosis with over 90% accuracy.

The initial symptoms can present as idiopathic Parkinson's disease and it may be some time before development of the symptoms that lead the neurologist to suspect PSP. Some patients may wait two – three years before diagnosis of PSP is reached.

Cianci (2012) suggested a useful acronym to aid differentiation between Parkinson's disease and PSP – **FIGS**

---

**F** – Frequent falls, generally backwards

---

**I** – Ineffective medication, Parkinson's disease medication generally doesn't work

---

**G** – Gaze palsy

---

**S** – Speech and swallowing changes

---

No diagnostic tests exist but imaging techniques including SPECT, PET and MRI scans are carried out primarily as a means to exclude other neurological conditions. An MRI scan can show the presence of the 'hummingbird sign' in some people with PSP. The 'hummingbird sign' is an indication of midbrain atrophy which has been shown to be reliably predictive of PSP.

**PSP is a very individual condition, with a wide variation in symptoms and rate of progression requiring increasing care and support from the multidisciplinary team.**

Any questions? Contact our helpline:  
Telephone **0300 0110 122** Email: [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

---

---

Early symptoms may include the inability to use one side of the body.

---

---

## Presentation – CBD

### DESCRIPTION

Corticobasal Degeneration (CBD) is a progressive neurological disorder characterised by nerve cell loss or deterioration and atrophy of multiple areas of the brain. The progression of the disease may be slower than the progression of PSP. It is defined by the accumulation of tau protein, which forms neurofibrillary tangles in the brain. Many of the management interventions for PSP are often helpful in CBD.

The principal areas of the brain affected are:

- The basal ganglia
- The cortex.

People diagnosed with CBD may occasionally go on to develop features of PSP and vice versa.

### ONSET

- Early symptoms may include:
- The inability to use one side of the body, for example the loss of use of one hand
- Myoclonus and apraxia (jerky, awkward movements)
- Complex unintentional movements of the limb interfering with normal tasks ('alien limb')
- Increased behavioural changes
- Problems with memory
- Asymmetric – not occurring equally on both sides of the body.

### EPIDEMIOLOGY

- Can affect people from 40 onwards – average age of onset 60 – 70
- Slightly more common in women.

### INCIDENCE AND PREVALENCE

- Prevalence: 4.9–7.3 per 100,000.

### DIFFERENTIAL DIAGNOSIS

Differential diagnosis is as PSP.

---

---

## Aetiology and treatment

### FAMILIAL

Less than 1% of those with PSP have a family member with the same condition. A variant in the gene for tau protein called the H1 haplotype, located on chromosome 1, has been linked to PSP, but this genetic variation is common and is not enough to cause PSP on its own.

The role of genetics in PSP is currently under investigation, but the likelihood of the condition being passed on through genetic mutations is very small.

### CAUSES

Despite the recent advances in the understanding of the biology of PSP, the cause of the disease is still unknown.

Almost all cases appear to be sporadic. It has been suggested that both environmental and genetic influences may be involved. Around 20 percent of the UK population carry a gene which provides a weak susceptibility to PSP (though with a very low level of risk), but the disease itself appears to be triggered environmentally or selectively.

### TREATMENT

There is currently no treatment or cure for PSP or CBD. Management is based around symptom control and quality of life hence early diagnosis and referral to specialist multidisciplinary teams is key. Later sections in this booklet discuss medication that can be offered in the management of symptoms.

More information into the causes and treatment of PSP and CBD can be obtained from the PSP Association website at [www.pspassociation.org.uk](http://www.pspassociation.org.uk)

## Red Flags

The difficulty in diagnosing PSP has led to the creation of red flags to act as warning signs that may raise clinical suspicion of PSP.

Think about PSP when seeing patients diagnosed with movement disorders e.g. Parkinson's disease where there has been a poor response to Levedopa, more rapid progression of symptoms and the development of clinical features not seen in Parkinson's disease.

### What to look for in a patient consultation:

|    |                                |   |
|----|--------------------------------|---|
| 1  | <b>Falls</b>                   | Often backwards and without warning   |
| 2  | <b>Postural instability</b>    | Axial rigidity  |
| 3  | <b>Slowness of movement</b>    | Bradykinesia  |
| 4  | <b>Motor recklessness</b>      |   |
| 5  | <b>Eye problems</b>            | Restricted eye movement. May describe finding it difficult to walk downstairs due to problems with down ward gaze, reduced blink, double vision |
| 6  | <b>Speech</b>                  | Slurring of speech, soft voice  |
| 7  | <b>Swallowing difficulties</b> | Liquids/and or solids, excessive saliva   |
| 8  | <b>Cognitive changes</b>       | Change in personality, irritability, apathy   |
| 9  | <b>Emotional lability</b>      |   |
| 10 | <b>No presenting tremor</b>    |   |

If your patient has one or more of these symptoms please refer to Neurology and state PSP in the referral letter.

If your patient has one or more of these symptoms please refer to Neurology and state PSP in the referral letter.

Any questions? Contact our helpline:  
Telephone **0300 0110 122** Email: [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

# The management of PSP and CBD

## MONITORING AND ASSESSMENT

The multidisciplinary team (MDT) offers the best approach to management and works towards improving quality of life. A large number of health and social care professionals will need to be involved with each patient at some stage.

The MDT should use a patient-centred holistic approach to ascertain the patient's physical, social, emotional and spiritual needs each time they see them.

In order to manage the presenting symptoms and problems the individual may present with, it may be appropriate for the GP to refer to the following members of the MDT:

A large number of health and social care professionals will need to be involved with each patient at some stage.

|   |  |
|---|--|
| <b>Parkinson's Disease Nurse Specialist</b> | Medication and management of complex issues                                    |
| <b>Physiotherapist</b>                      | Mobility (gait, falls and balance)   |
| <b>Occupational Therapist</b>               | Mobility, postural issues and equipment  |
| <b>Speech and Language Therapist</b>        | Communication aids/swallowing difficulties                                     |
| <b>Dietitian</b>                            | Weight loss, lack of appetite  |
| <b>Orthoptist</b>                           | Problems with vision   |
| <b>Continence Nurse Advisor</b>             | Bladder dysfunction  |
| <b>Community Matron</b>                     | Manage complex issues of the condition   |
| <b>District Nurse</b>                       | Support and case management  |
| <b>Community Psychiatric Nurse</b>          | Behavioural problems   |
| <b>Psychologist</b>                         | Fear, anxiety, depression  |
| <b>Palliative Care Team</b>                 | Pain control, counselling and psychological support, day therapies and respite |
| <b>Social Worker</b>                        | Difficulties in activities of daily living                                     |
| <b>PSP Association</b>                      | Support for individual and family  |

Expert care and advice can be accessed through the PSP Association via our helpline on 0300 0110 122 or our website [www.pspassociation.org.uk](http://www.pspassociation.org.uk)

---

## MANAGING SYMPTOMS

See relevant sections in this booklet.

## THINKING AHEAD – ADVANCE CARE PLANNING (ACP)

The GP is in an ideal position to help the patient talk through options for their care preferences at the end of life stage. Early assessment for inclusion on the Palliative Care Register and access to specialist palliative care is needed due to the rapidly degenerative nature of both conditions.

---

Early discussions regarding ACP are particularly important because of communication difficulties that people with PSP can experience.

---

Early discussions regarding ACP are particularly important because of communication difficulties that people with PSP can experience. This makes it vital to discuss and seek their views on treatment and management early, when they are still easily able to express and communicate their desires and wishes.

## ADVANCE DECISION TO REFUSE TREATMENT (ADRT)

An ADRT is a decision that an individual can make to refuse specific treatments in certain circumstances for the future. This can include the right to refuse life-sustaining treatment.

Before making an ADRT the contents should be discussed with the GP to ensure that the patient is clear regarding which treatments they wish to decline and that they have a full understanding.

If this is made, it is good practise for a copy to be kept by the practice with the patient's record.

It is important that all people with PSP are placed on the GP Supportive Care Register within the practice.

Please refer to the *Palliative Care* section of the booklet for further information.

---

## Movement and mobility

The patient will be affected by problems with movement and mobility throughout all stages of the condition including:

- Poor balance
- Early falls and frequent falls, often backwards and without warning
- Unsteady gait with reduced arm swing
- Nuchal rigidity (stiffness in the nape of the neck, often accompanied by pain and spasm on attempts to move the head)
- Motor recklessness
- Difficulties with complex and fine motor skills
- Bradykinesia
- Muscle rigidity
- Loss of ability to maintain weight-bearing position

### CONSIDER

- Equipment assessment to support movement and activities of daily living
- Assessment for a specialist wheelchair
- Assessment for walking aids
- Telecare falls sensors
- Education of carer on likelihood of increased movement impulsivity and decreased safety judgement with disease progression.

### MEDICATION TO CONSIDER

- Levodopa – Sinemet/Madopar
- Dopamine agonists – pramipexole/ropinirole (can have a limited effect on patients)
- Amantadine
- Muscle relaxants – baclofen, clonazepam, botulinum toxin.

---

## REFER ON TO

- Physiotherapist – for individual and also carer, for education
- Occupational Therapist.

Whilst impulsive movement is a moderate impairment, individuals exhibiting this require a high level of supervision due to the high risk of falls and constant support from the carer. This may mean that a greater level of support at home is required at this time.

You may also wish to refer to *A Guide to PSP and CBD for Occupational Therapists*.

Any questions? Contact our helpline:  
Telephone **0300 0110 122** Email: **helpline@pspassociation.org.uk**

---

---

## Pain

People living with PSP may have physical pain caused by:

- Muscle rigidity
- Muscle cramps
- Immobility
- Ice-cold sensations in extremities.

### MEDICATION TO CONSIDER

- Simple analgesia, e.g. long lasting NSAIDS (joint pain)
- Baclofen
- Clonazepam
- Amitriptyline (beware cognitive disturbance)
- Gabapentin (neuropathic pain)
- Pregabalin (may also help with sleep).

### SKIN SENSITIVITY

- Good skin and pressure care is vital. District nurses for pressure-relieving equipment.

### REFER ON TO

- Local Pain Clinic
- Physiotherapist
- Occupational Therapist
- Complementary Therapist
- Pain that is hard to manage – specialist pain clinic or palliative care team.

Communication problems may make understanding the type and source of pain challenging and should be taken into consideration.

The PACSLAC is an appropriate assessment tool if communication is difficult.

Involvement of the person's carer and wider family is essential in understanding the nature of the pain and how to alleviate it.

---

## Speech and Communication

The majority of people with PSP will develop communication problems at some point as the condition progresses and changes may happen quickly. Individuals may experience:

- Palilalia – repetition of syllables or whole words the patient is saying
- Slurred speech
- Hypophonia – low volume voice
- Hypomimia – reduced facial expression
- Mobility and restricted eye movement may limit communication
- Repetitive speech and verbalisation of 'no' and 'yes' when the opposite is meant
- Echolalia – repetition of syllables or whole words that others are saying
- Very erratic speech, with few remaining words intelligible
- Cognitive problems which may lead to withdrawal or difficulty engaging in social interaction.
- Problems with executive function may make response times longer
- Supranuclear gaze palsy will make eye contact more difficult in social interaction.

### CONSIDER

- Prism glasses available from the PSP Association which may help with the use of communication aids
- Speech applications on tablets or lightwriters.

### REFER ON TO

Early referral to Speech and Language Therapist who will:

- Arrange for assessment and provision of communication aids and strategies
- Advise on strategies for communication
- Occupational Therapist – environmental controls.

Liaison with clinical psychologist if cognitive problems are impacting communication.

---

## Dysphagia

Difficulties with swallowing are common in PSP and swallowing changes impact an individual's ability to maintain appropriate nutrition and hydration. These changes can greatly affect the psychological wellbeing of the person living with PSP and their family.

---

Early sensitive discussions regarding PEG feeding should be held with the individual and their family carers and repeated frequently to identify what their wishes may be in the future.

---

Early sensitive discussions regarding PEG feeding should be held with the individual and their family carers and repeated frequently to identify what their wishes may be in the future. This procedure is best tolerated whilst the individual is relatively fit.

Problems may include:

- Coughing when drinking fluids
- Coughing and aspirating whilst eating
- Being at further risk of choking or aspiration if cognitive issues lead to cramming mouth with food and gulping of liquids
- Excess runny or thick saliva
- Potential drooling as a result of poor lip seal and control of facial muscles
- Recurrent chest infections.

### CONSIDER

- Assess nutritional intake and weight
- Altered meal patterns can be helpful, i.e. instead of three meals a day take a 'little and often' approach – consult dietitian
- Alter consistency of diet – consult dietitian or speech and language therapist
- Possibility of thickening fluids – consult speech and language therapist
- Carer support.

---

## MEDICATION TO CONSIDER

### Thin runny saliva

- Atropine eye drops administered under the tongue (can cause confusion)
- Glycopyrronium bromide (glycopyrrolate)
- Hyoscine (should be used with caution as can sometimes cause confusion in PSP/CBD)
- Botulinum toxin to the salivary glands
- Amitriptyline (beware of cognitive disturbance)
- Swallow prompt apps on smartphones or tablet computers.

### Thick saliva

- Mucodyne
- Nebulised saline
- Pineapple, apple, papaya or lemon juice
- Check fluid intake.

### Dry mouth

- Artificial saliva sprays – Glandosane
- Good mouth care – consider referral to specialised dental services.

## REFER ON TO

- Speech and Language Therapist – Swallowing assessment and discussion of PEG insertion
- Dietitian
- Occupational Therapist.

---

## Bladder and bowel

Problems with the bladder and bowel can range from minimal to severe impairment throughout the condition. Individuals may experience:

- Urinary frequency and symptoms of overactive bladder
- Difficulty initiating flow and poor flow
- Feeling of incomplete emptying of bladder
- Nocturia
- Urinary incontinence
- Frequent urinary tract infections.

### MEDICATION TO CONSIDER

- Movicol
- Laxido
- Molaxole.

### REFER ON TO

- Dietitian
- Continence adviser
- Occupational Therapist
- Physiotherapist
- District nurses.

Any questions? Contact our helpline:  
Telephone **0300 0110 122** Email: **helpline@pspassociation.org.uk**

---

## Vision

Problems with vision can include:

- Slower or hypometric eye movement
- Blurred and double vision
- Vertical gaze palsy – restricted eye movement with slowing of the up and down gaze
- Photophobia
- Excessive lacrimation
- Tunnel vision
- Blepharospasm
- Decreased blink rate – causing corneal problems and dry eyes
- Eyelid apraxia – inability to open the eyes at will, may lift brows up to ‘help’ the eyelids.

### CONSIDER

- Education of family and carer regarding possibility of falls due to problems with downward gaze
- Prism glasses (available from the PSP Association)
- Ptosis props and Lundie loops to help alleviate blepharospasm and apraxia of eyelid opening
- Tinted wraparound sunglasses.

### MEDICATION TO CONSIDER

- Artificial tears or eye sprays
- Ocular lubricants
- Botulinum toxin.

### REFER ON TO

- Orthoptist
- Occupational Therapist.

## Cognition

Changes in executive function, behaviour and mood are common and include:

- Slowness of thought processes
- Impaired ability to manipulate acquired knowledge
- Difficulty concentrating
- Poor judgment and planning
- Apathy/disinterest/withdrawal
- Lack of motivation
- Impulsivity (including motor recklessness)
- Poor sleep
- Impaired recognition of emotions and lack of empathy
- Changes in mood, including depression
- Emotional lability and personality changes.

Timely assessment is key and a base line assessment should be carried out.

### REFER ON TO

- Clinical psychologist
- Community nurse
- Occupational Therapist
- Physiotherapist.

---

It is important for people living with PSP to be given the opportunity to make advance decision whilst they still are able to do this.

---

Supporting carers is vital. Care givers often feel unprepared and understandably struggle. Access to psychological support for both the individual and the carer/family should be offered as appropriate. Education for the carer and family may be useful in managing challenging or unexpected behaviours.

The various cognitive effects of PSP can lead to the reduction or loss of mental capacity. It is important for people living with PSP to be given the opportunity to make advance decision whilst they still are able to do this.

You may also wish to refer to *A Guide to Cognition for Health and Social Care Professionals*.

---

## Palliative care

---

Access to early palliative care is helpful in allowing individuals and families to plan for the future

---

PSP and CBD are rapidly progressive conditions with a wide range of symptoms. Access to early palliative care is helpful in allowing individuals and families to plan for the future, discuss wishes and make choices that are right for them. In addition to symptom management the subject of referral needs to be approached sensitively. Inclusion of the palliative care team early on helps to support both those affected by the conditions and the professionals involved.

It is important that all people with PSP should be placed on the GP Supportive Care Register and discussed regularly in a multidisciplinary Gold Standards Framework meeting. This will ensure that planning future care can be undertaken whilst linking the opinions of the numerous professionals involved.

Discussions about Advance Care Planning/Advance Decision to Refuse Treatment ensures that patient's wishes are respected at each stage of the disease. The progressive nature of the cognitive changes seen in PSP often impact on an individual's abilities to maintain capacity as defined by the Mental Health Capacity Act 2005. Early discussions around Advance Decision to Refuse Treatment (ADRT), Advance Care Planning (ACP) and Lasting Power of Attorney (LPA) should be considered and the individual/family supported to explore these issues if they wish to do so.

Areas that may need to be discussed and considered in PSP include:

- Where a person wishes to be cared for
- Alternative methods of feeding e.g. feeding tubes
- Whether they would want to have cardiopulmonary resuscitation
- Antibiotic therapy.

Hospices often run a day service which allows patients to access therapies such as massage, develop a rapport and gain input from palliative care specialists and help ease the transition to advanced disease and end of life. This can also often provide significant support and respite for carers. Speaking to your local hospice to see what can be offered to PSP patients can be very fruitful for the patient/carer and their GP.

When end of life care is required the person with PSP and their families will be better supported by staff they already have a rapport with, and who understand the complexities of a neurodegenerative illness.

---

## END STAGE

Many people living with PSP and their families fear end of life will be caused by a choking episode. This is rarely the case and they require reassurance regarding this. The most common cause of death is from aspiration pneumonia. Death in the majority of cases is very peaceful and pain free if managed well. Towards the end of life, anxiolytics and analgesia should be prescribed in line with good end of life care principles according to local protocols and palliative care departments.

Family and carers will need practical and emotional support. Care plans and information must be shared by all members of the care team and adequate nursing cover maintained.

The end stages can be difficult to detect in PSP, this stage may last six to eight weeks and indicators may include:

- Reduced levels of consciousness
- Inability to eat and drink (if no PEG tube in place)
- Severe infection that could not be treated in the home environment (hospital admissions may have previously been refused)
- Fall or major fracture
- Rapid and significant weight loss (*ref PSP Association 2012 Best Practice in PSP*).

---

## Support for families and carers

Being a carer for someone with a long-term condition can be overwhelming. There can be many strains upon the relationship which can be particularly challenging for carers, especially if the person with PSP experiences changes in personality, or a loss of apathy or ability to recognise emotions in others.

It may be appropriate or helpful to arrange some time to talk to the carer without the patient present, perhaps, whilst blood tests are being done. This can help offer support, find out which issues are burdening or distressing for them (these may be different than the patient's concerns) and allow time to provide support networks.

Carers of people with PSP need advice, support and information to help them to make sense of what is happening, to enable them to continue in their caring role, and help them plan for the future.

It is important to check with the carer at every stage that they feel able to continue with their caring role.

Carer stress is common and they may experience any of the following:

- Guilt
- Disbelief
- Helplessness
- Anger
- Depression
- Sleep disturbances
- Inability to concentrate
- Weight loss/gain
- Inability to cope
- Financial pressures
- Loss of social networks
- Anxiety.

---

It is important to check with the carer at every stage that they feel able to continue with their caring role.

---

---

## MANAGEMENT

- Support carers by regular and separate assessment of their own needs
- Allow time for the carer to discuss how they are feeling
- Refer on to social services for a Carers Assessment – this should anticipate need and must be outcome-based and reviewed on a regular basis
- Ensure access to community matron or district nurse
- Carers should be registered as carers on the practice register and be given priority for treatment
- Respite – discuss if required and facilitate this if necessary
- Signpost to PSP Association and carers associations for support.

Many carers will not ask for help until they reach crisis point and GPs are in a position to prevent this.

People with PSP should be booked for double appointments due to slowness of speech and movement. Home visits will be necessary as the disease progresses.

---

## Psychological support

People with PSP, their families and carers often experience considerable psychological and emotional distress. Loss of hope, fear, lack of control, anxiety and frustration are just some of the emotions that people may experience. All of these will affect the patient's other holistic needs.

Ensure those affected by PSP have an appropriate level of information about their condition. Be guided by the patient and carer's preferences for how much information they would like.

---

Ensure those affected by PSP have an appropriate level of information about their condition.

---

Distress is likely to vary throughout the course of the disease and patients should be referred for counselling. Identify an individual to provide ongoing support and information. This may include support from local psychological services or the local hospice.

People may lose their social support due to changes in occupation, hobbies, relationships and in their physical abilities. It is common for people to become socially isolated, which can have an impact on their physical and psychological wellbeing.

- Consider referring to hospice day therapy services
- Give information on support available from PSP Association.

Depression is not always easy to differentiate from sadness, but treatment is likely to have a positive effect. Consider screening for anxiety and depression in patients and especially carers where persistent low mood or hopelessness is expressed.

Consider SSRIs such as citalopram or sertraline.

Any questions? Contact our helpline:  
Telephone **0300 0110 122** Email: [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

---

---

## Research

The PSP Association (PSPA) funds and promotes ground-breaking research to improve the lives of people affected by PSP/CBD and is dedicated to finding treatments and ultimately a cure.

Its strategic research aims are:

- To improve early diagnosis of PSP/CBD
- To understand the causes of PSP/CBD and the chain of events leading to its development and progression
- To develop new treatments and improve clinical care and social support for people affected by PSP/CBD
- To stimulate the search for a cure.

PSPA will do this with the support of the UK PSP Research Network.

The PSP Research Network is made up of seven centres with PSP specialisms – the leading one based at University College, London with others in Oxford, Cambridge, Newcastle, Manchester, Brighton and Newport.

They work together in collaboration, sharing their database of patients and samples.

These centres are involved in a study called, PROSPECT, which focuses on patients that have been newly diagnosed.

The project is the first of its kind in the UK and involves two studies. A longitudinal study sees patients monitored on a regular basis through MRI scans, blood and fluid samples.

A separate, remote, study involves patients donating blood samples through their local hospitals.

For further information on PSPA research projects visit <http://www.pspassociation.org.uk/research/>

---

## BRAIN DONATION

Brain Banks have been established to collect tissue samples and whole brains donated by people with PSP and others with neuro-degenerative disease.

Examples include the Queen Square Brain Bank in London and the Cambridge Brain Bank. These are a valuable source for research which will enable researchers to better understand what causes PSP/CBD and how the diseases progress. In the long term, this will enable us to develop a much-needed diagnostic test and an effective treatment.

The Sara Koe PSP Research Centre (SKRC) is based at the Institute of Neurology in London. The SKRC administers a PSP DNA and Brain Bank and is closely linked to the Queen Square Brain Bank which stores the brains of people who have died from various neurodegenerative diseases as well as the brains from disease-free donors.

People living with PSP will often enquire about brain donation, as will their family members who wish to do something positive to help with research. In the first instance they can discuss this with their specialist, or call the telephone number below for information and support.

### **Queen Square Brain Bank**

The Administrator – 020 7837 8370

### **Cambridge Brain Bank**

Senior Research Nurse – 01223 217336

Information on other local brain banks can be found at <https://www.hta.gov.uk/guidance-public/brain-donation>

---

## Further information for health and social care professionals from the PSP Association:

### **An Introduction to PSP and CBD**

An information leaflet for the newly diagnosed explaining both conditions and services available through PSPA.

### **Pathway of Care for PSP**

*Full pack – contains standards of care, best practice guidance, symptom snapshots and care pathway visual*

This is a guide to the standards of care and best practice for all those working with, providing services for and supporting people living with PSP and CBD.

### **Pathway of Care for PSP – a quick guide**

An overview of the Pathway of Care for PSP.

### **A Guide to Cognition for health and social care professionals**

This booklet contains information on cognitive and behavioural change, and practical tips on management.

### **A Guide to PSP and CBD for Occupational Therapists (OTs)**

This booklet aims to provide OTs with information about PSP and CBD and aims to address issues at different stages of progression. It also provides practical suggestions to aid therapeutic intervention.

### **PSP Fact Card**

A credit sized fact card which includes a brief description of PSP and PSPA contact details.

## The PSP Association (PSPA)

PSPA is the only national charity offering advice, support and information to people living with PSP and CBD, while supporting research into treatments and ultimately a cure for these conditions.

PSPA offers:

- Support for people affected by PSP and CBD
- Provides information, educational resources and training opportunities for health and social care professionals
- Promotes and sponsors worldwide research through the PSP Association Research Network.

### THE PSP ASSOCIATION HELPLINE AND INFORMATION SERVICE

Our Helpline and Information Service is the first point of contact and gateway to Association services and support. We offer information, practical and emotional support to people living with PSP, their carers and families and PSPA staff and volunteers.

Our telephone and email service is confidential and we aim to respond to all telephone enquires within 24 hours (during normal office hours) and email enquires within two working days. Our opening hours are Monday to Friday 9am until 5pm and then 7pm until 9pm.

Telephone: 0300 0110 122. Email: [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

We can provide you with a wide range of information services, resources and keep you up to date with our regional and national educational events.

If you call us and are unable to get through, please leave a message with your name and telephone number and we will return your call as soon as we can.

Any questions? Contact our helpline:  
Telephone **0300 0110 122** Email: [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

## LOCAL GROUPS

These provide informal opportunities for people living with PSP, carers, family and friends, health and social care professionals, to share information and encouragement.

Many of the volunteer-led groups invite visiting speakers such as benefits advisers and health and social care professionals, to share expertise on managing PSP on a daily basis.

If you would like more information on our local groups, or just wish to go along to find out how valuable they are for people living with PSP/CBD, please contact the helpline or visit our website

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

## SPECIALIST CARE ADVISERS

Our team of Specialist Care Advisors (SCAs) work to ensure that people affected by PSP have access to good local support and a local keyworker to co-ordinate care wherever possible (or acting as such where one is not available).

They are on hand to help local health and social care providers gain a greater understanding of the care needs of people with PSP and to ensure that services meet agreed standards of care. SCAs also focus on raising the profile of PSP by informing, influencing and educating through the delivery of regional training and educational events.

## OUR WEBSITE

Our website offers accurate, timely, and relevant information on all aspects of PSP, including the latest news on research and events.

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

## PSP FORUM

Our forum can be accessed via <http://psp.healthunlocked.com>

This gives individuals the opportunity to connect online with others affected by PSP and those working with the condition.

---

## Acknowledgements

Dr Boyd Ghosh, Consultant Neurologist at University Hospital Southampton NHS Foundation Trust and Salisbury NHS Foundation Trust. Honorary Teacher at the University of Southampton

Dr Sarah Agyekum, GP Retainer, London

Dr David Oliver, Consultant Physician in Palliative Care – Medway Community Healthcare

Anna Kent, Neurological Conditions Clinical Specialist, Neurological Conditions Clinical Specialist Team (NCST), Central & North West London NHS Foundation Trust

Dr Louise Wiblin, Senior Neurology Registrar, South Tees NHS Trust.

## References

A reference list of the evidence to support this guide is available on request. Please make your request by email to **helpline@pspassociation.org.uk**

Or write to us at

Helpline and Information Services  
The PSP Association  
167 Watling Street West  
Towcester  
NN12 6BX

## We welcome your views

The PSP Association encourages feedback about any aspect of the information we produce. Your feedback is really important to us, as it helps to develop new material and improve our existing information for the benefit of people living with PSP/CBD and those who care for them.

Please send your feedback to: **helpline@pspassociation.org.uk**

---

Registered in England number: 2920581.  
Registered charity numbers:  
England and Wales 1037087/Scotland SC041199

Copyright PSP Association 2015



The PSP Association  
PSP House  
167 Watling Street West  
Towcester  
Northamptonshire  
NN12 6BX

Email: [psp@pspassociation.org.uk](mailto:psp@pspassociation.org.uk)

Telephone: 01327 322410



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