

Progressive Supranuclear Palsy

**PSPA**



# Carer's Information Pack

Your personal guide to PSP

**Working for a world free of PSP**



# Carer's Information Pack

## Introduction



Welcome to The PSP Association. This pack is designed to help you manage PSP or CBD, particularly if you are caring for someone with either condition.



We hope that the pack answers many of the questions you may have, be it about arranging financial support or managing the symptoms, as and if they arise.

We're also here to help.

Several of us at The PSP Association have cared for our own family members with PSP or similar conditions. All of our Specialist Nurses have valuable and relevant professional experience.



We've split the pack into four manageable sections to make it easier for you to find the information you need.

Remember that we're here to support you on your journey. We also remain focused on finding treatments and an eventual cure for these diseases, as well as encouraging the health and welfare services to provide the best possible support for you.

Do let us know if we can be of service in any way.

With best wishes,

**Fergus Logan**

Chief Executive

Please note: the term PSP is used throughout to refer to both PSP and CBD.

## Acknowledgements

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# About PSP and CBD



# What is PSP?



Progressive Supranuclear Palsy (PSP) and Cortico Basal Degeneration (CBD) are closely related neuro-degenerative diseases. They are caused by the progressive death of nerve cells in the brain, leading to difficulty with balance, movement, vision, speech and swallowing.



## Progressive Supranuclear Palsy (PSP)

The condition is so called because it is:

- **Progressive** - it gets steadily worse over time
- **Supranuclear** – it damages parts of the brain above the pea-sized 'nuclei' that control eye movements
- a **Palsy** – it causes weakness



### The main symptoms

Early symptoms may include loss of balance and unexpected falls (usually backwards), stiffness and eye problems. These can include difficulties in looking up or down, focusing, double or tunnel vision and dislike of bright lights.

Some people can experience behavioural and cognitive changes - depression, apathy, clumsiness, or tiny, cramped handwriting. Early on, symptoms may resemble those of other neuro-degenerative diseases such as Parkinson's disease, Alzheimer's disease, Motor Neurone disease or Multiple System Atrophy. As a result many people are initially misdiagnosed.

As PSP progresses, symptoms increase. There may be problems with swallowing, slurred speech, recurrent falls, irritability and apathy, slowness of response and severe difficulties walking. Sometimes the eyelids close involuntarily and it becomes increasingly difficult to look up or down. Emotional lability, such as laughing or crying inappropriately, may be another feature and there can be incontinence.

The average life expectancy is around seven years from onset. However, every case is different – there is considerable variation in the symptoms and rate of progression in individuals.

## What causes it?

PSP is associated with an over-production of a protein called tau in certain areas of the brain. In PSP it forms into clumps - or neurofibrillary tangles - which are believed to damage nerve cells. The actual cause of PSP is still unknown but it is thought to result from a combination of genetic and environmental factors. Suggestions for possible causes have included head injury, viral infections and neurotoxins in the environment but none of these is yet supported by scientific evidence.

## Is it inherited?

There is no evidence to suggest that PSP is inherited but research has indicated there may be some genetic susceptibility that makes some individuals more at risk of developing PSP than others.

## How common is it?

Research into the prevalence of the disease suggests that in the UK there are around 4000 people living with PSP. This research is now over 10 years old and some neurologists believe the number could be higher.

It is often initially diagnosed as Parkinson's disease, a stroke or a brain tumour due to the slowness of movement and balance problems, or as Alzheimer's because of changes in mood, intellect and personality. PSP often goes undiagnosed in the elderly, especially those in residential care homes. Data held by The PSP Association indicates that 3 out of every 4 people with PSP are initially misdiagnosed and often repeatedly misdiagnosed with other medical conditions.

## How is PSP diagnosed?

There are no simple tests to diagnose PSP. Brain scans can help neurologists with diagnosis by excluding other conditions. Diagnosis relies on a characteristic mix of symptoms but can only be confirmed by post mortem examination of brain tissue.

## What treatment is available?

There are no effective treatments for PSP. However there are many therapies to help manage symptoms and people with PSP should regularly see a neurologist and palliative care team. In the future, we hope that research will lead to new treatments to stop or slow down the progression of the condition.

## Cortico Basal Degeneration (CBD)

CBD is another degenerative brain disease, affecting people from the age of 40 onwards. Although there are biological similarities to PSP, with similar nerve cell damage and build up of tau protein in the brain, the classical clinical picture is quite different.

- **Cortico** - affecting the brain cortex
- **Basal** - also affecting other parts of the brain such as the basal ganglia
- **Degeneration** - death of nerve cells in the brain

### The main symptoms

CBD often starts with progressive numbness and loss of use of one hand. There can also be jerking of the fingers, slowness and awkwardness and an 'alien limb' – with complex unintentional movements of one limb causing problems with normal motor tasks.

Gradually the arm and/or leg on one side is affected and then the arm and/or leg on the other. People with CBD often have trouble controlling one hand when doing everyday things such as writing or tying shoelaces – tasks that involve individual muscle movements we take for granted. There can also be disturbance of the eye movements but these are normally less debilitating than in PSP.

### How common is it?

As yet, there has been no research into the prevalence of CBD but we do know that it is much less common than PSP. Again, people are often initially misdiagnosed as having Parkinson's disease or a stroke.

### Is there any treatment?

At the moment there is no treatment to stop or slow the progression of CBD. However, many symptoms can be treated and are usually managed in a similar way to those for PSP.





# Living with PSP



The way PSP affects people in the early stages varies from person to person. The changes may be subtle and symptoms may be similar to those found in other conditions, making diagnosis difficult. There is no definitive test, diagnosis is made by clinical observation considering the diagnostic criteria. It may therefore take some time to obtain a correct diagnosis.



Many people present with a movement disorder, are referred to a clinic specialising in Parkinson's disease and are treated accordingly.

## After Diagnosis



When PSP is suggested, families will probably never have heard of it. They are likely to experience a mixture of relief at being given an identifiable name, and distress at receiving this diagnosis. Understandably, people find it hard to absorb the information straight away.

These feelings are perfectly natural and in the following days and weeks, families may experience a mixture of denial, anger, panic or grief.

Most families find that these feelings subside as support becomes available and they have time to come to terms with the diagnosis. Individual family circumstances and the response of your local health and social care services will have a bearing on the length of time this process takes.

## Daily Living

PSP has a wide range of symptoms and the severity and progression varies widely between individuals, so don't believe that everything you hear will happen in your case.

If and when you need advice on the management of a particular symptom, contact your neurologist, GP or other relevant local health professional.

Some people with PSP can experience low mood or lack of reasoning. Both symptoms can be difficult to accept, but as carer, it's important to understand that this type of behaviour is not intentional. You may also need to explain these changes to family and friends.

Our advice is always to try and lead as normal a life as possible within the limitations you both face.

Don't forget that the person with PSP needs to understand – where possible – that you, as carer will be under a lot of physical and emotional stress.

For example, if the person with PSP suffers from poor balance, try and explain the risk and consequences of a fall. This may help prevent them from insisting on doing things without help.

It is helpful for you both to share short term goals. For example, trips out and holidays (with careful forward planning) can be memorable occasions.

As carers, it's important you give yourself enough attention. Carers have a tough job and it's easy to feel guilty. But it's no good giving your physical and emotional all in the short term, if that means you can't cope later on. Pacing yourself and ensuring your needs are met are as important as meeting the needs of the person with PSP.

Health and Social Care workers are professionals used to dealing with sensitive issues and should be sympathetic to a family's needs. The PSP Nurse Specialists speak to many people in similar situations and will also be able to help.

Role reversal can be one of the toughest challenges for a family dealing with PSP. Many women take on tasks previously done by the man and likewise many male carers may find themselves in a more domestic role. Financial decisions may also have to be made. This may be especially difficult for older people with other health problems.

## Support is a Joint Effort

Ensuring that a family affected by PSP is supported is a joint effort involving

- The person with PSP
- The immediate carers and family

- The health and welfare services
- Many voluntary and charity organisations, including The PSP Association.

In particular, people with PSP and carers need to support each other to ensure that their needs are met.

Sometimes families can feel isolated, but there are many people who can help. They won't be needed at once but can be introduced as the need arises or when suggested by your Neurologist, GP or Nurse Specialist.

Your location will have an impact on how much you have to do yourself to ensure you receive the help you'll need. Some areas allocate case managers from either the NHS or Local Authority. They'll work on your behalf to coordinate any health, welfare and financial support you need.

In other areas, you may have to take on more of this task yourself, but there are many voluntary organisations that can assist. Many of those organisations are mentioned elsewhere in this guide.

## Communication

Many problems occur with the health and welfare services because people don't understand the implications of PSP. This means that you as carer, and the person with PSP must be honest and open with each other on what their needs are.

Sometimes, the challenge is to ensure that the health and welfare services understand what is needed.

Since PSP is a comparatively rare illness and often misdiagnosed, most health and welfare workers will not have seen a case before. You may know more about it than they do. In order to help them give you as much support as is available within local resources, we suggest that you:

- Press your case politely, but firmly. Health and welfare resources in many areas are stretched, and it is a sad fact that those who press their case tend to get noticed.
- Prepare for meetings or visits to assess your needs. What do you want to get from the visit, and what information would help the health or social worker? Prepare a short summary as follows:

- Give an explanation of what PSP is, possibly using copies of our literature or directing them to our website, [www.pspeur.org](http://www.pspeur.org)
- Include information about the person who has PSP (some call it “The Story of Me”) – a few paragraphs indicating family and career achievements and interests, to help personalise them as individuals, not just ‘another case’.
- Share PSP Association contact details, for example, encouraging the visitor to call our PSP Nurse Specialist for advice where you judge it to be useful.
- Consider not just today’s needs, but ask the visitor to ensure that tomorrow’s are also covered. PSP is progressive, and assistance can take time to organise.

## The Internet

If you are not connected to the internet, it is worth considering the possibility. There are four main reasons we recommend that you “get connected”:

- There is a vast amount of information on the health, welfare and charity services available to you locally and nationally. Most forms you need to fill in can be downloaded from the internet, and telephone numbers and contacts are easily found.
- You will probably be spending more time at home, and the internet offers everything from:
  - Easy and cheap communication with friends and family.
  - Banking and shopping: all the major supermarket chains have an on-line ordering service that they deliver to your door.
  - Leisure: everything from finding holidays that suit your circumstances to renting video tapes or DVDs.
- It is very easy to use. Most local libraries run free (or at worst very cheap) courses in how to find information or send e-mails. A couple of hours training is enough to give you the essentials. It is also possible to access the internet at a local library if you do not have a computer.

## Summary

There are no hard and fast rules and sadly no easy answers when living with PSP, but the golden rules are:

- Help is available, do not be afraid to ask for it
- Sometimes a problem shared is a problem halved. Our nurses are on the end of the phone when you feel you need to talk, or are just having a bad day and feel you want to offload some of your worries.
- You are not alone in your struggle.
- You can only do your best, none of us is perfect.
- Try to find something, however small, in each day to enjoy.
- Plan for the future (e.g. adaptations to the home, obtaining specialist equipment).
- Live for today.



# Symptoms

Symptoms



# Mobility



PSP damages neurons in the brain, especially the regions associated with movement and balance control. This can lead to slowness in movement, impulsiveness (particularly in sitting and standing up), muscle rigidity and deterioration in posture, gait and stamina.



Difficulties with movement and balance are a common feature of PSP. It's important to minimise the resulting number of falls. These are often backwards, without warning and can result in serious injury.



After diagnosis, you should be referred to a physiotherapist (PT) and occupational therapist (OT). You can do this through your GP or refer the person yourself at the local hospital or community health centre. There are also many independent therapists who run clinics and make home visits (see useful addresses).

Many shops offer a wide range of aids to help with daily living and getting around the home safely. However, if the aid is complex or expensive, it's best to get the opinion of an OT or PT first. A good source of independent advice is available from Assist UK who are funded by the NHS. They operate over 50 showrooms that have a wide range of aids, as well as a bulletin board for second-hand items. Visiting is usually by appointment, to ensure that an OT is available to discuss your needs. You can find out where your nearest showroom is at [www.assist-uk.org](http://www.assist-uk.org) or by calling 0870 770 2866.

## Physiotherapy

The physio will do an assessment and can advise on:

- Stretches for stiff muscles and joints to prevent or relieve rigidity.
- How to improve or maintain muscle strength with general or specific exercises or provide an exercise programme for the person to follow at hospital or at home.

- Techniques to help make movements more automatic, such as walking, sitting down and standing up. These are some of the things that can become more difficult as the disease progresses.
- How to help maintain independence in daily life. For example, difficulties with getting in and out of bed can be helped by the PT teaching a different way of going about it.
- Advise and train you as a carer on the safest and best ways to help.

Try and make exercises part of daily life. General exercises should include walking. As mobility is reduced, a series of passive stretching exercises can be performed. These can improve circulation and also offer an opportunity for some physical contact. You may find the person tires more easily, so short periods of exercise on a regular basis will be more beneficial than long sessions every now and then.

Muscular rigidity and a reduction in movement can lead to muscle cramps or spasms. Treatments can include:

- Gentle massage, heat packs or passive exercises to the affected area.
- Muscle relaxant medications.
- Botulinum Toxin (Botox) injections. Botox is a nerve toxin injected in small doses into tense, rigid muscles to relieve pain and spasm. In PSP, Botox is usually administered into the shoulder area and into the eye muscles. The spasms are reduced because the injected muscles are paralysed or weakened. Treatments will probably need to be repeated every 3-4 months. Your neurologist will usually offer these treatments in a botox clinic.

### Walking Frames and Balance

PTs, sometimes in conjunction with OTs, provide and advise on walking aids such as wheeled frames and wheelchairs (see below). Walking frames should be solid and weighted to avoid backward falls. Lightweight aluminium Zimmer frames are not appropriate for use by people with PSP. A "U-Step" frame<sup>1</sup> may be beneficial, without the laser beam function. (*The physio will know what this is*). A few people with

<sup>1</sup> U-Step is a brand name, developed for people with Parkinson's Disease. They can include a laser beam function, which is expensive and generally not needed for people with PSP

PSP find that wearing built up shoes helps shift their weight forwards, reducing the tendency to fall backwards.

## Occupational Therapy

An OT should provide an assessment of the home environment and advise on equipment and strategies to maximise safety and wellbeing. Funding may be necessary to provide adaptations to a home and Social Services can advise.

Essential equipment could include:

- Grab rails or bars - firmly mounted bars are very useful in helping standing transfers from bed, shower and toilet.
- Ramp access - steps and changing levels are a major hazard.
- Stair rails or through floor-lift – especially if living on a single floor is not feasible.
- Commode chairs – to ease difficulties of transferring to the toilet, especially if access is restricted.
- Wet rooms or shower cubicles with side doors – offer commode chair or wheelchair access.
- Hoists – these can be free standing or ceiling mounted to ease transition from, say chair to bed.

## Wheelchairs

Some see the decision to use a wheelchair as a loss of mobility and a sign that the disease is progressing. We believe you should take a positive view – consider the increase in mobility and quality of life it could bring.

Your PT, or possibly your OT should advise you on wheelchairs. When choosing consider the following:

- Home layout. Some wheelchairs are too large to negotiate corners and may be unable to cope with more than one step.
- Ramp access both in the home and in the garden/drive.
- Individual comfort. For example, some people might require a high-backed chair with head or neck support.

- Your ability as the carer - pushing a wheelchair can be hard work! Electrically powered chairs with carer-operated controls are available.
- Will one chair be enough or do you need one for inside and one for outside? A wide range of wheelchairs are available, including:
  - Internal chairs that are light, compact and easy to manoeuvre .
  - Through wheelchairs that can be used both inside and outside if internal access is good and pavements are reasonably smooth.
  - Outside wheelchairs that are very robust, weatherproof and able to handle rough pavement and high kerbs.

Using two wheelchairs of course assumes that transfers can easily be achieved between them.

- How much do you need or want to use a car? There tend to be two solutions:
  - Chairs that can be folded and carried separately in the boot, requiring minimum changes to the car, but needing the user to transfer between chair and car.
  - Car or van conversions that permit the chair to be driven straight into a converted vehicle, saving the need to transfer but with the cost of a converted car or van to consider.

Our section Getting About contains further information.

### Home environment

Changes to the home environment are often necessary so plan ahead. As PSP is a progressive illness, some future needs can be anticipated and equipment can be accessed and installed ahead of time. A safe home can help people maintain independence for as long as possible and reduce the risk of falls.

General advice to maximise the quality of life for the person and to minimise the risk of falls includes:

- Carry out your own risk assessment. Falls are most likely to occur when you need to make a change of level or of direction.

- Look at the normal pattern of walking through the house, paying particular attention to these hazard points and consider what can be done to minimise the possibility of a fall. Also consider how to minimise impact if a fall does occur.
- Remove obstacles/hazards that can result in a fall or injury e.g. loose rugs, unguarded open fire, uneven surfaces and cluttered floor space.
- Visual problems can also increase the risk of falls, especially if the person has difficulty looking down. Discuss this with your GP and ask for a referral to an orthoptist to see if prism lenses might help.
- Surround the person with the things that they may need. A forgotten box of tissues or a pair of glasses may prompt someone who is unsteady to go in search and this may result in a fall.
- Impulsive behaviour. Some people tend to be impulsive attempting to carry out tasks that risk injury. This may be a symptom of the condition, but it might be because they want to remain independent. Where possible, both of you should talk about the consequences of a fall, and weigh them against the benefits of the behaviour.
- Consider using elbow pads, hip protectors or a special helmet that can be obtained from the surgical appliance department at the local hospital. These can be useful for people with severe balance problems who continue to be mobile and could again minimise the consequences of a fall. Discuss with your OT or PT.
- An alarm system. Panic buttons can be worn around the neck and used if one is alone and has a fall or an injury (see useful addresses). However, if the person also suffers from short-term memory loss (see our section on Behavioural Changes) then be aware that they might not always use it, or may use it inappropriately.

## Useful addresses and websites

### **The Disabled Living Foundation**

Helpline: 0845 130 9177 (charged at local rate)

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

### **Government Services**

Access to public services on holidays and financial support

[www.direct.gov.uk/](http://www.direct.gov.uk/)

### **The Chartered Society of Physiotherapists**

Tel: 020 7306 6666

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

### **Medic Alert**

Tel;020 7833 3034

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



# Symptoms **Sight**



People with PSP may experience visual problems that can't be corrected by glasses.



Problems with the control of eye movements occur in PSP and may occur in CBD.



## The most common symptoms are:

- Double vision
- Tunnel vision where the field of vision is reduced.
- Blurred or misty vision.
- Slow jerky movements. This can make it difficult to read from one line to the next, or to look from one point to another. Often this can cause communication problems – not making eye contact can often be seen as a lack of interest.
- Difficulty looking down. This can cause problems with cutting up food and accurately getting food to the mouth. It also means that the risk of falls increases.

## Other symptoms that may affect the eyes are:

- Less frequent blinking, causing dry eyes, irritation or eye infections.
- Involuntary eyelid closure (blepharospasm), making reading and watching television difficult.
- Difficulty opening eyelids (apraxia of eyelid opening)
- An aversion to bright light (photophobia), especially bright sunshine.
- Occasionally the eyes can water, but the tears trickle from the outside corner and don't wash over the eye. That means the cornea can remain dry, causing ulceration in extreme cases.

## Fortunately there are plenty of ways of coping with these problems.

- Make sure all items the person needs, such as food and drink, are well within the field of vision.
- Remove as many trip hazards as possible.
- Eye drops such as viscotears or hypromellose can be used to help moisten dry eyes. Use these even if the eyes are watering as described above. Liquid paraffin can also be used at bedtime, but this can blur the vision and shouldn't be used during the day.
- A product called Eye Logic or Actimist can be sprayed on to the closed eyelid as an alternative to using drops.
- Double vision can be aided by putting a patch over one eye or taping over one lens.
- Prism glasses may be useful and are available from The PSP Association (Tel: 01327 322410). Please discuss with your nurse specialist. Prism film can also be added to prescription glasses.
- Wrap-around sunglasses or tinted lenses will help with photophobia, (available from RNIB).
- Ptosis crutches, sometimes known as lundie loops, can be fitted to glasses. These are wires that hook gently into the eyelid to hold it open.
- Injections of Botulinum Toxin (botox) can be used to treat blepharospasm and apraxia of eyelid opening. In severe cases where botox injections haven't helped, surgery might be suggested to rectify involuntary closing of the eyelid.

If visual issues are a problem, ask to be referred to an orthoptist, ophthalmologist or eye specialist. They may assess the person with PSP as sight impaired, or for those with severe blepharospasm, severe sight impaired. This diagnosis means that talking books and newspapers will be available free of charge. There could also be other advantages such as reduced council tax, television licence and travel costs.

## Useful contacts

The services provided below are either free or low-cost. If you have a certificate from an ophthalmologist stating you are blind or partially sighted you will be entitled to receive free Talking Books and Newspapers.

Local Library: Access to a range of spoken word cassettes and CDs through its interlibrary loans scheme.

Calibre Cassette Library: Unabridged books on cassette:

Tel: 01296 432 339 or [www.calibre.org.uk](http://www.calibre.org.uk)

Listening Books: Abridged and unabridged books on tape for people with disabilities other than sight loss:

Tel: 020 7407 9417 or [www.listening-books.org.uk](http://www.listening-books.org.uk)

RNIB Talking Book Service: Unabridged books in a special CD format with the capacity to hold a whole novel:

Tel: 0845 762 6843 or [www.rnib.org.uk/talkingbooks](http://www.rnib.org.uk/talkingbooks)

Talking Newspaper Association: National newspapers and magazines on cassette tape and in electronic format

Tel: 01435 866 102 or [www.tnauk.org.uk](http://www.tnauk.org.uk)

You can also use the Internet: [www.revealweb.org.uk](http://www.revealweb.org.uk) is the national database of accessible resources. Log on to search the catalogue and find out what is available.





# Speech



PSP also causes problems with speech. Some people may also experience memory and personality changes that can affect their ability to communicate successfully. (See our separate leaflet on Behavioural Changes.)



Speech and Language Therapists (SLTs) can offer positive support for people with PSP. At the onset of any speech problems, ask for an early referral to a SLT. Ideally, ask to see a specialist who has had some experience of managing PSP. The SLT may carry out therapy to improve speech or suggest strategies and aids to help maintain communication for as long as possible.



## How can behavioural changes affect communication?

PSP can affect the ability to sequence both actions and thoughts. It can be difficult for people to explain a sequence of events in the right order. They can also have problems doing two things at once, such as walking and talking. Keeping a sequence of actions in their head can be difficult too, so you may have to guide them one step at a time.

People affected by PSP can also have difficulty with abstract thinking. They might also struggle if you're talking about topics involving emotions or where they have to use their imagination. They may lose interest in things they used to enjoy and be more irritable.

Processing information and working out how to respond can also take much longer. If others aren't aware of this, they could assume the person isn't taking any notice, or if it's a group chat, the conversation may have moved on. Make sure you allow extra time for a response – sometimes several minutes. Not letting someone respond can cause frustration and a great sense of social isolation.

Facial expressions can be considerably reduced in PSP and there is often reduced eye contact. This can give the impression that the person isn't interested and can make others feel it's not worth making the effort.

People with PSP may have difficulty suppressing actions. This can lead to echolalia – where they repeat back the word or phrase that has just been said. It's really important to make others aware of this, especially when asking questions involving a choice. For example, if they are asked: 'would you like to go out or stay at home?' they might repeat back 'stay at home' when they may not mean that.

Encourage family and friends to phrase questions carefully so that there are no misunderstandings.

### Speech Symptoms in PSP

Speech can become difficult to understand or slurred. This is because areas of the brain controlling movement of the tongue, lips and throat may be affected. Parts of the brain responsible for the 'fine-tuning' of movements can also be affected. The type of dysarthria (speech problem) can be broadly separated into three types:

- Spastic Dysarthria. The voice sounds strained or harsh and speech is slow and slurred. This happens because the muscles involved in speech become tense and stiff, making it hard to produce a voice and use tongue and lips to sound words properly.
- Hypokinetic Dysarthria. Speech becomes quiet - to the point of being difficult to hear - and very fast. Sometimes it can be so quick that stammering occurs, making it hard to understand. Occasionally, there can be repetition of sounds, syllables or words (pallilalia). The voice may sound croaky or breathy.
- Ataxic dysarthria. Speech sounds slurred and people can struggle with longer words. Movements of the tongue are slow, making it difficult to coordinate all the movements of the tongue, lips, and voice. As a result, people with ataxic dysarthria are often mistakenly thought to be drunk.

**More people have spastic dysarthria and some have hypokinetic dysarthria. Ataxic dysarthria is less common. Sometimes there can be a combination of two or all three conditions.**

## How can the Speech and Language Therapist help?

If speech has recently become affected, the SLT may work directly with the person with PSP. The therapy could include exercises that target symptoms such as reduced volume or increased speech rate. They might use techniques such as 'Think Loud' to improve volume, pacing boards or regular pausing to help make speech easier to understand.

They can also provide tailored guidance for professional carers, friends or relatives on how best to help with communication difficulties.

If communication through speech is particularly difficult, there are many supportive aids and strategies worth trying. They include:

- Boards featuring the alphabet to give listeners the first few letters of a key word. Often this is enough to allow the listener to understand phrases and short sentences. (A metal tray with magnetic letters is a handy way to spell out words.)
- Voice amplifiers can help make quiet voices audible. These do need relatively good speech to work effectively.

Telephones are available to amplify outgoing speech and some have a 'hands-free' option. (Brochures are available from BT.)

- If speech becomes more problematic, there are electronic communication aids that require pointing or touching keys. For example, to answer the telephone, an aid that has only a few recorded messages such as 'This is Harry, I'm fine' may be helpful. Other communication aids will provide a wide range of spoken or written phrases or sentences by typing in or just by pressing a few keys.
- Visual problems can make many communication aids hard to use. It's important that the person is assessed by a SLT with specialised knowledge of communication aids. Some of them can be expensive and they're not always available for loan. Check out the cost, benefit, and likely period of usage before thinking about buying.
- If the person can't point or press keys and buttons due to limb weakness use communication aids for them by scanning. You move your finger slowly across a range of options, such as letters or pictures and they indicate (through nodding, blinking or other means) when to stop. This is quite a slow process but can work for many.

***If you'd like to see and possibly try out a range of available aids, or are unable to contact a SLT, you could visit a NHS Communication Aid Centre for advice and training. There are at least 19 Centres throughout the UK. To find your nearest, try [www.cacfrenchay.nhs.uk](http://www.cacfrenchay.nhs.uk), click "Other Services" and then "Other Communication Aid Centres".***

It's best to introduce communication aids early on, before the person is dependent on them. This allows plenty of time to get used to them and can prevent frustration.

A carer suggests...

*'If speech becomes difficult and it seems that it might be lost altogether, another method might be useful. It works on a 'squeeze my hand' basis.*

*The simplest method is that the carer goes through the letters of the alphabet and the person with PSP squeezes their hand at the right letter.*

*There is a more sophisticated version – a double squeeze which takes you into code. This way each letter of the alphabet has a meaning, such as 'I'm hungry', 'I'm tired', 'be quiet!' or other simple phrases.*

*It can be quite fun to set up and if the more sophisticated communications systems fail to work because of brain reaction time, lack of eye coordination or lack of finger dexterity, this method is an effective means of communication.'*

***See also communications advice for hospital and care staff in Help & Support section.***

I'll point to the first letter of the word to help you understand what I'm saying.  
 Sometimes I'll spell out the whole word.

A	B	C	D		New Word	1	2	3
E	F	G	H			4	5	6
I	J	K	L	M	N	7	8	9
O	P	Q	R	S	T		0	
U	V	W	X	Y	Z			





# Swallowing Difficulties



Difficulties with feeding, eating and swallowing are common in PSP and can occur fairly soon after diagnosis. These can occur for a variety of reasons at different stages of eating and swallowing.

- Being able to see your food is an important part of the enjoyment of eating. Hand/eye coordination and an ability to lift cutlery to the mouth is necessary to feed oneself. The difficulty with downward eye movement found in PSP makes this quite difficult.
- Behavioural problems that can occur with PSP can lead to over-filling of the mouth or drinking too quickly, which in turn can lead to food or liquid going down the wrong way into the lungs (aspiration).
- Lastly, the fine control and coordination of the muscles of the mouth and throat that are needed for safe chewing and swallowing can be affected in PSP.

Difficulties with swallowing can lead to coughing and choking, weight loss, dehydration and chest infection or at the most extreme, pneumonia.

Coughing when eating or drinking is an indication that food or liquid has 'gone down the wrong way' into the airway. If this occurs regularly, it can cause chest infections or pneumonia. Mild or moderate problems with swallowing (dysphagia) can often be satisfactorily managed with advice from the Speech and Language Therapist.

The signs that could alert you to a swallowing problem are:

- Coughing or choking when eating or drinking
- Taking a long time to finish meals
- Food sticking in the throat
- A 'wet' or gurgly voice quality
- Taking a long time to swallow what is in the mouth or food being left in the mouth
- Increased phlegm in the throat and difficulty clearing this
- Weight loss
- Repeated chest infections

The person with PSP may be able to accurately describe their swallowing problem. Others may not realise they have a swallowing problem and may take too much food or liquid into the mouth too quickly, leading to coughing or choking. Sometimes, food or liquid can go down the wrong way into the airway with no coughing. This is called 'silent aspiration'.

**If any of the above problems are observed, request an urgent referral to a Speech and Language Therapist. They will carry out an assessment of swallowing and suggest management strategies.**

**However, some simple changes, listed below, can make eating and drinking less troublesome.**

	Things to look out for	What Helps?
1	Over-filling mouth or eating/drinking too quickly	<ul style="list-style-type: none"> <li>• Supervise all meal times.</li> <li>• Use frequent verbal prompts to remind the person to swallow each mouthful and to take appropriate amounts. (<i>Using a smaller spoon also helps to measure out the amount of food per mouthful.</i>)</li> <li>• Give small amounts of liquid at a time and top up frequently. Using a spouted cup with a fine spout can help control the amount of liquid being delivered.</li> </ul>
2	Spillage of food/drinks down the front of clothes (caused by difficulty looking down)	<ul style="list-style-type: none"> <li>• Raise the level of the plate nearer to eye-level to reduce the need to look down e.g. with height-adjustable table or tray on legs placed on table (see OT, District Nurse or equipment shop).</li> </ul>
3	Difficulty clearing phlegm from throat (due to thickened saliva, weak cough and weakened swallow)	<ul style="list-style-type: none"> <li>• Cut down on dairy products as these can thicken secretions.</li> <li>• Sips of hot water with slices of lemon or orange juice. Citrus juices can thin secretions making them easier to swallow.</li> <li>• Inhale steam. This will thin secretions, making them easier to swallow.</li> </ul>
4	If chewing becomes laborious, slow and difficult	<ul style="list-style-type: none"> <li>• Avoid chewy food – eat softer, moist food such as braised steak, tender chicken or fish in sauce.</li> </ul>
5	Food sticking in the throat	<ul style="list-style-type: none"> <li>• Avoid dry, crumbly food.</li> <li>• Add gravy or sauces.</li> <li>• Alternate food with sips of drink.</li> </ul>
6	Difficulty swallowing tablets	<ul style="list-style-type: none"> <li>• Take one tablet at a time.</li> <li>• Put each tablet in a spoonful of yoghurt, porridge or something similar to swallow.</li> </ul>

Sometimes swallowing deteriorates to the extent that it's not possible to maintain adequate nutrition and hydration and/or avoid the risk of chest infection or pneumonia. In these cases it might be possible for the person with PSP to receive supplementary hydration and feeds through a tube placed directly into their stomach. This is called a Percutaneous Endoscopic Gastrostomy (PEG). See Later in Life section.

A member of the team working with you would discuss this fully with you to ensure you have sufficient information. If they can swallow safely, the person with PSP may still eat and drink small amounts with 'top up' from the PEG feeds. This can take away the pressure of meeting all the fluid and nutritional requirements orally. The decision to go through this procedure is a very individual one and must be made by the person with PSP, their family and carers and their Consultant.

You can discuss the pros and cons of PEG feeding at any time with a member of your team and ensure your wishes regarding your future care are documented in an Advance Care Plan.

If the person with PSP has a PEG fitted, they may continue to have difficulties swallowing their saliva. This can result in coughing and is often worse at night.

We all swallow our saliva several times per minute. Someone with PSP may swallow much less frequently and this can lead to saliva becoming thick and concentrated. Alternatively, their swallow function may be impaired so that when they attempt to swallow their saliva it can go into the airway. If the person with PSP appears to be coughing on thin saliva, i.e. the coughing occurs unexpectedly and does not sound 'rattly', the following may help:

- Medication to reduce the production of saliva e.g. amitriptyline tablets or botulinum toxin injected into the salivary glands. It is important to speak to your Consultant about this.
- Saliva is more likely to go into the airway if the person is lying flat at night. Using an extra pillow or two can assist.

If the person appears to be coughing to attempt to clear thick secretions and the cough sounds rattly, use of saliva reducing medications may not be the correct solution but again, it is important to speak to your Consultant about this. Try the following:

- Inhaling steam will help to thin secretions making them easier to cough up. If the person is able to take liquids orally, sips of warm water with lemon can also help to thin the secretions.
- Reduce intake of dairy produce, which can thicken secretions.
- Ask for a referral to a Physiotherapist. They can give chest Physiotherapy and suggest exercises that may help to loosen secretions, making them easier to cough up.





# Saliva



Saliva plays an important function. It helps break down food and protects the mouth from drying out and cracking. Too much or too little saliva can cause problems. Some people may experience discomfort and embarrassment due to reduced saliva control.



We all produce about a litre and a half of saliva every day, but in health we swallow frequently. People with PSP have a reduced swallow reflex causing saliva to pool inside the mouth. Saliva can also be thick and difficult to swallow and some medication can cause saliva to dry up leading to a dry mouth.



Here are a range of ideas for you to try in different situations. These are suggestions only and shouldn't replace individual assessment and treatment by a Speech & Language Therapist.

## What can we do if there is too much saliva?

### Some foods and drinks can help reduce saliva production:

- Ginger tea has a drying effect on the mouth. Sucking pieces of dried ginger may help if there is no risk of choking
- Dark grape juice
- Sage
- Pineapple juice or try sucking fresh pineapple as it has a cleansing effect on the mouth

### Posture

- Sometimes improving posture can improve the problem. Ensure the person keeps their head as upright as possible
- When eating and drinking sit as upright as possible. Support the head and neck with pillows if needs be.

## Routine

- Remind the person to keep their mouth closed when reading, listening or watching television.
- Keep tissues or a towel handy. Dabbing rather than wiping saliva will cause less irritation to the skin. Vaseline or a barrier cream can help prevent the corners of the mouth from getting sore.
- Remind them to swallow saliva at regular intervals, say every two minutes. The SLT can recommend a swallow reminder if the person is becoming forgetful.
- Always ensure the mouth is as clean as possible to reduce the amount of bacteria. Regular check ups with your dentist will identify oral health problems.

## Lip Strengthening Exercises

- Push lips forward as if saying 'oo'
- Spread lips as if saying 'ee'
- Repeat 'oo''ee' 6 times
- Puff air into your cheeks for as long as possible
- Press your lips tightly together as if saying 'mm'.

Do this series of exercises several times a day if possible. Ask the person's physiotherapist if you need more advice.

## Over the counter remedies

- Be cautious with medicines such as sea-sickness tablets, cough and cold remedies, which claim to dry up saliva. In some they give temporary relief, but cause side effects in others. Discuss this with your SLT, nurse specialist, consultant or GP before proceeding.

## Medication

Discuss the following possible treatments with your GP **before** proceeding:

- Atropine eye drops used under the tongue are beneficial in most cases. These are used because a side effect of the eye drops is the drying of secretions. They are **NOT** to be used in the eyes! One to

two drops of 0.5% three times a day is the usual dose. People find them most beneficial when used about 30 minutes before meals. They can take a few weeks to become effective, so persevere. (Please note: this medication is unlicensed and your GP may be reluctant to prescribe it. Also, some areas of the country have difficulty accessing atropine -an alternative is Mydrilate 1%).

- Glycopyrronium can be prescribed to dry out the mouth, providing some temporary relief. This comes in tablet form and is usually taken in 1mg up to three times a day.
- Other medications can have the beneficial side effect of reducing the amount of saliva in the mouth. An example is amitriptyline, which can be used for pain, to aid sleep and also as an antidepressant.
- Hyoscine is commonly used for the drying of saliva, often in a patch form. However, experience shows that in PSP and CBD it can sometimes cause confusion or hallucinations (especially in the elderly) and should only be used if your neurologist recommends it.
- Botox injections into the saliva glands, although not licensed for saliva reduction, can be used at the discretion of the consultant to limit drooling. These can be effective for some patients and treatment usually lasts 3-4 months, but can be repeated.

### What can we do if the saliva is too thick?

- Ensure enough liquids are consumed. Aim for 1½ to 2 litres a day.
- Avoid mucus-thickening agents such as dairy products.
- Avoid caffeinated drinks and alcohol.
- Suck sugar-free boiled sweets to stimulate saliva production and swallowing.
- Steam inhalation, humidification and nebulisers can be helpful. Discuss these with your GP or nurse.
- Pineapple juice or pureed pineapple helps dilute saliva.
- Suck on crushed ice.
- A water-based gel can be spread over the lips and inside the mouth to maintain moisture at night.

If these methods aren't successful, some medication can increase the amount of saliva in the mouth and suction machines can be used for sticky or excessive saliva. Ask your GP or Nurse for advice.

### **What can we do if there is too little saliva?**

- Some foods can make dryness in the mouth worse. Ask your GP to refer you to a dietician.
- Ensure you are drinking enough fluids – around two litres a day. Take frequent sips of water throughout the day.
- Avoid alcohol and smoking as these can both increase dryness.
- Avoid mouthwashes that contain alcohol.
- Use lip balm or Vaseline on the lips regularly.
- Remove dentures at night.
- Limit sweets to sugar-free to prevent tooth decay.
- Discuss the use of artificial saliva (available on prescription) or alternative medication with your GP or neurologist.



# Oral Health



As people with PSP may have other physical and psychological health issues, care of the mouth and teeth can often be neglected.



Poor oral health can cause problems such as bad breath, loss of appetite and weight loss, self-esteem issues and pain. Because of swallowing difficulties, there is an increased risk of food going down the wrong way into the lungs (aspiration). This can lead to serious chest infection or pneumonia.

Good oral hygiene is essential. It won't prevent aspiration but will help to minimise excess bacteria from the mouth entering the lungs if it does happen.



Brush the teeth twice daily with fluoride toothpaste to help prevent potential problems and keep the mouth clean and comfortable.

## Common Oral Health Problems

- **Reduced Saliva**

If the person has swallowing difficulties, there is an increased risk of tooth decay, inflammation of the mouth and throat, infection and pain. Often there is less saliva, making swallowing even more difficult. Reduced saliva leads to:

- An unpleasant taste in the mouth and coated tongue.
- Increased levels of bacteria leading to problems such as tooth decay and a higher risk of chest infection if this saliva goes into the lungs.
- Food residue remaining in the mouth, increasing the number of bacteria present.

- **Dry Mouth (xerostomia)**

Xerostomia is the feeling of dryness in the mouth, generally unrelieved by drinking fluids. It is usually, but not always, caused by medication. There are around 400 medicines currently known to cause reduction in salivary flow.

**Having a dry mouth can cause:**

- An increase in dental decay
- Difficulty in wearing dentures, particularly upper dentures
- Increased effort to swallow food
- Burning sensation to the tongue, dryness and cracking
- Increased susceptibility to infection and ulceration
- Dryness and cracking of the lips

Dry mouth symptoms are debilitating so it's vital that mouth care is carried out regularly either by the person or their carer. Always discuss the situation with the GP or dentist as treatments may vary.

Often artificial saliva can provide some relief. There are also medications to stimulate saliva production. Regular sweet sucking is not advisable (even sugar-free varieties) as sugar and acid content can damage tooth enamel. Frequent sips of iced drinks or sprays of water can help, as can regular applications of a lip balm such as Vaseline.

In the later stages of the disease, pineapple juice (either frozen or fresh) can refresh the mouth and stimulate saliva production. Use with caution in the early stages, as the high sugar and acid content of the fruit can damage tooth enamel.

- **Damage to teeth from medication**

The use of regular liquid medications can cause damage. Ensure a GP or pharmacist reviews these regularly. Sugar-free medicines should be prescribed if they're available. This is particularly important for medicines taken just before bedtime as sugar can coat the teeth and cause overnight damage. Ensure that if medicines containing sugar are taken, teeth are brushed thoroughly afterwards.

- **Damage to teeth from sugary foods and drinks**

Sugar produces plaque acids in the mouth, which coat the teeth and cause decay. Left untreated, toothache will develop. The best way to reduce sugar intake is to restrict sugary foods and drinks to mealtimes only. Snacks in between meals should be sugar free wherever possible.

- **Gum disease**

Poor brushing technique can often leave plaque at the gum margins. This can irritate the gums and cause them to become swollen and to bleed. Left untreated, swollen, irritated gums can recede and cause teeth to become loose and fall out. There are two ways to prevent gum disease:

- Visit the dentist regularly. The dentist can remove plaque build-up to promote healthy gums.
- Brush gums gently, as well as teeth, twice daily with a fluoride toothpaste. See the section below on brushing teeth effectively.

- **Mouth ulcers**

Mouth ulcers (apthous ulcers) are very common and can cause much pain and discomfort. However, they are easily treated with an over the counter surface anaesthetic, such as Bonjela. Antibiotic mouthwashes are also available from the GP or dentist or if there is extensive ulceration an anti-viral preparation such as Acyclovir may be prescribed. Usually mouth ulcers last for no longer than two weeks but if they persist beyond this, or you have any concerns, contact the dentist or family doctor.

## Brushing Teeth Effectively

The single most important thing to maintain good oral health is to brush teeth thoroughly twice a day, morning and night. Brush each surface of each tooth with a soft to medium textured toothbrush and fluoride toothpaste, working your way systematically round the mouth from back to front. Only use a small amount of water to wet the brush to ensure maximum benefit from the fluoride in the toothpaste and to avoid choking.

## There are various products widely available to help:

- **'Curved' toothbrushes**

The 'Collis Curve' or 'Super Brush' toothbrushes are handy for brushing someone else's teeth or for anyone with limited dexterity when brushing. They have a specially curved head that removes plaque from all the surfaces of the teeth at the same time, gently working below the gum line and stimulating circulation and general gum health.

- **Interdental cleaning**

Tooth brushing does not remove plaque from interdental areas (in between the teeth) or beneath the gum margins. These areas are more susceptible to decay and gum disease. Dental floss, tapes and interdental brushes can be used. The dentist can explain how to use them.

- **Interdental brushes**

Small tapered bristle brushes that clean between teeth. They are easily used by both the person and their carer.

- **Dental floss and flossing**

Dental floss is a fine cord, sometimes waxed and/or flavoured. Waxed floss is advised, as it is less likely to catch or tear on rough tooth surfaces. Some brands are impregnated with fluoride to help protect tooth enamel. If used incorrectly, floss can damage the gum tissue and over time may saw into the tooth itself. It therefore requires skill and manual dexterity to be used correctly. A dentist or hygienist will demonstrate how to floss correctly.

- **Other oral hygiene aids**

These include gauze strips and pipe cleaners for cleaning wider gaps between teeth, wooden sticks and toothpicks, rubber and plastic tipped devices. If used incorrectly, they may cause trauma. They should be used only if recommended by a dental health professional.

## Using Mouthwashes and Other Preparations

Mouthwashes help removal of debris from the mouth and provide a sensation of freshness. Many products contain alcohol that can irritate the lining of the mouth so always seek advice from the dental team or pharmacist if you are concerned. The following are widely available:

- **Chlorhexidine gluconate (e.g. Corsodyl)**

Chlorhexidine gluconate is the most effective anti-plaque agent and is available as a mouthwash, gel and spray. It can cause staining of teeth but this is reversible and can easily be removed by the dentist. All traces of toothpaste must be removed by rinsing before using chlorhexidine to maximise its effects.

- **Sodium bicarbonate**

Sodium bicarbonate (baking soda), although frequently referred to in nursing literature, is not recommended for mouth care. There is little evidence to confirm its usefulness in cleaning the mouth and it can cause chemical burns if incorrectly diluted.

## As time progresses

As the illness becomes more advanced, the person may develop swallowing difficulties and risk of choking. If this is the case, ensure that the person's chin is tilted forward and a towel or small bowl used to catch excess fluid and prevent choking.

Sometimes, due to muscle spasms, the person can't open their mouth fully, making it difficult to maintain good oral hygiene. A good technique is to use two toothbrushes – one to gently insert between the top and bottom teeth on one side of the mouth to gain access, while using the other brush to clean the teeth on the other side. The carer can then swap the brush to the opposite side and continue brushing the teeth. It can take up to 10 minutes to thoroughly clean the mouth so make sure enough time is allowed in the daily routine.

Mouth props are also available and can be used to assist access to the mouth.

A mouth prop ('Bedi Finger Prop') or bite support made of plastic worn on the index finger of the carer's non-brushing hand can be placed between the jaws to help to keep the mouth open. For further information contact your occupational therapist or dentist.

It may also become more difficult to use a normal manual toothbrush. However, there are aids that can make this task more manageable:

- **Adaptations for toothbrushes**

Encourage the person to be as independent as possible for as long as possible. There are many devices designed to enable them to maintain their own oral care, such as chunky handles that can be fitted onto an ordinary toothbrush, or again, the 'Collis Curve' toothbrush (see end) can be useful. Discuss this with the occupational therapist.

- **Electric/powering toothbrushes**

An electric/powering toothbrush is easy to use, promotes independence and makes it easy to reach difficult areas at the back of the mouth. Powered brushes with an oscillating/rotating action remove plaque more effectively and studies have shown they can reduce gingivitis (gum disease) when used for at least three months. To be effective, electric toothbrushes should be kept fully charged and the head changed every three months.

## Denture care and conditions caused by dentures

Partial dentures with wires and clasps are more prone to collect food and need more attention. Teeth next to partial dentures also require extra care. Problems can occur when dentures are not looked after and poor hygiene is often associated with yeast infections of the mouth (such as candida or thrush).

### Tips for Denture Care:

- Rinse dentures after eating. Clean thoroughly at night.
- Remove dentures at bedtime to allow the mouth's soft tissue to rest. Store in a named container of plain tap water. Cleaning tablets such as Steradent only need to be used if infection is present or if advised by the dentist.
- Dentures can be labelled with the individual's name. This is useful if the person needs to be admitted to hospital. For more information on denture labelling contact your Community Dental Department.

- If dentures become loose, contact the dentist. Loose dentures can easily be adjusted using a process called 'relining'.
- Dirty or poor fitting dentures can cause irritation or infection of the lining of the mouth. A common but easily treated infection is denture stomatitis. This is a condition of the palate caused by poor denture hygiene and wearing dentures at night. It causes red areas of the palate, but the person rarely complains and may be completely unaware of the condition. If you're concerned check with the dentist or GP.

### How to Access Treatment

After diagnosis visit the dentist as soon as possible so that a treatment plan for oral help can be developed. Dental services can be accessed in several ways:

- **General Dental Practitioners**

Dental registration lasts only for 15 months so ensure they have a check up at least annually to maintain this. Check access arrangements before you go.

- **Community Dental Team**

A service provided by local healthTrusts (PCT or H&SCT) and clinics, usually based in health centres or hospitals. This service is available to individuals who need specialist care and treatment. To access this service, contact your local health centre or GP surgery.

- **Domiciliary visits**

A service run by the Community Dental Team for people who are housebound, usually due to a medical condition, and are unable to attend dental clinics. To access this service, contact your local health centre or GP surgery. Some general dental practitioners may also offer domiciliary visits.

## Main dental health messages

**To promote good oral health there are four key messages:**

- Regular check ups at the dentist by attending at least every year and more frequently if recommended.
- Reduce the consumption and frequency of sugary foods and drinks. Try to eat a healthy, balanced diet.
- Brush teeth twice daily with a fluoride toothpaste.
- Rinse dentures after eating, and clean thoroughly at night.

## Useful Websites

- **British Dental Association** ([www.bda.org](http://www.bda.org)) A national professional association for dentists. Directory of dentists available.
- **BDA Smile** ([www.bdasmile.org](http://www.bdasmile.org)). The independent dental advice site for patients by the **British Dental Association**. With easy to use sections for Children, teenagers, adults and seniors
- **British Dental Health Foundation** ([www.dentalhealth.org.uk](http://www.dentalhealth.org.uk)). Provides general information and resources.
- **The Irish Dental Health Foundation** ([www.dentalhealth.ie](http://www.dentalhealth.ie)). Contains information on all aspects of general dental care.
- **Find a Dentist** ([www.bda-findadentist.org.uk](http://www.bda-findadentist.org.uk)). Contact details for dentists in your area. You can also contact your local NHS Trust who will give you this information and advise you on who is currently registering new patients.
- **The British Dietetic Association** ([www.bda.uk.com](http://www.bda.uk.com)). Provides information about nutrition and diet and gives information about contacting dietitians in your local area.
- **British College of Occupational Therapists** ([www.cot.co.uk](http://www.cot.co.uk)). Has a useful link to help you locate occupational therapists in your local area.
- **Collis Curve toothbrush** [www.colliscurve.co.uk](http://www.colliscurve.co.uk) or tel 01934 862415.

## Bibliography

- Holistic Oral Care (2005), Janet Griffiths and Steve Boyle: 2<sup>nd</sup> Edition, Stephen Hancock Ltd
- The Scientific Basis of Oral Health Education (2004), RS Levine and CR Stillman-Lowe, BDJ Books, British Dental Association.





# Bowel and Bladder



People become increasingly immobile as PSP progresses. Constipation, lack of bowel control and urinary problems may develop.



## Bowel

Constipation is most commonly due to reduced physical mobility, poor fluid and dietary intake and sometimes medications including analgesics. To help prevent constipation:

- Develop a regular unhurried time for visiting the toilet.
- Encourage good posture while sitting on the toilet, upper body slightly forward with arms resting on the thighs. The occupational therapist can offer advice on this.
- Make dietary changes and include plenty of fibre – encourage the person to eat fruit, vegetables and wholemeal bread.
- Ensure they drink plenty of fluids throughout the day. This can become harder if swallowing problems occur.
- Keep the GP informed of any change in bowel habits, especially when the use of laxatives may be required. In the later stages, suppositories or enemas may be needed to encourage the bowels to open.
- Where possible, exercise will also help to keep the bowels moving.
- Pads may be required for bowel incontinence.



## Bladder

With increasing weakness and mobility problems, bladder management often becomes more difficult. People with PSP need more help to get to the toilet. Some need to be up frequently at night. This can be exhausting for both of you.

In PSP, two main problems can occur with the bladder:

- Feeling the need to go to the toilet frequently and urgently.
- Difficulty in initiating the flow to empty the bladder. In other words, the feeling of wanting to empty the bladder is present, but the bladder neck muscle won't relax to let the urine out, or it allows only some of it out. This can cause dribbling incontinence and can lead to bladder infections if untreated.

### To help promote urinary continence:

- Ensure that the Occupational Therapist has advised on and provided equipment where appropriate, such as grab rails, a raised toilet seat or a toilet frame.
- Adjust clothing to make things easier, such as adding Velcro fastenings or elasticated waistbands.
- Reduce the intake of stimulants such as tea, coffee and alcohol in the evening.
- Encourage a good fluid intake.
- Make it easier for them to let you know that they need the toilet. For example, provide a communicator board or a bell.
- Use aids such as a bottle or commode. These save time and lessen the danger of falling.
- Check with the GP that there is no underlying problem such as an enlarged prostate. This is a relatively common problem in men as they get older and symptoms also include urgency and frequency.
- Make sure there is no infection present. Your GP will ask for a sample of urine to be sent away for analysis.

- Ask the District Nurse about the availability of pads and pants, as well as mattress covers and absorbent sheets.
- Get advice from the local continence nurse.
- Talk to your GP about the possibility of prescribing medication to assist with severe cases of frequency. There are two different types of drug available. One acts by calming bladder contractions, allowing the bladder to relax. The other cuts down the production of urine for a period of eight to ten hours after administration - helpful for those suffering disturbed nights. No drugs however, are without side effects, and a full medical history will be considered when prescribing medication.
- Try a penile sheath (conveen) for men with incontinence. This is less invasive than a catheter, so reducing the chance of infection.
- Consider catheterisation, after discussion with the health care team either:
  1. A urethral catheter tube, inserted by a doctor or nurse. This is connected to a collecting bag strapped to the thigh, and emptied at a convenient moment.
  2. Supra-pubic, which involves a surgical procedure to insert the catheter through the lower abdominal wall directly into the bladder. This type of catheter also drains into a collecting bag.

Catheters carry a risk of infection, but can give freedom from worry about incontinence and can make every day life easier.





# Behavioural Changes



PSP can lead to a range of subtle changes in behaviour or personality.



## Possible symptoms include:

### Apathy

Some people become withdrawn or seem apathetic. This may show as a lack of interest in outings and holidays, in seeing old friends or members of the family. Often by taking control of the situation and being more assertive, you, as carer, can avoid becoming trapped in the home. Apathy can be linked to problems with communicating. As a carer, remember that PSP is probably at the root of these distressing changes.



### Irritability

People can become demanding, impatient and in some cases aggressive. Often they may fail to show gratitude. They may not be aware of this change, which makes your role as carer very hard. Neurologists who have studied the neuro-psychiatric changes believe there is probably some dulling of awareness in such cases.

### Irresponsibility or Lack of Understanding

Some carers talk about 'living with a stranger.' A typical example is someone with PSP who is prone to falling. The carer asks them to sit still while they leave the room, but the person with PSP fails to understand the instruction or the implication of not following it. The moment the carer leaves the room, the person with PSP gets up and falls over. Understanding these cognitive or behavioural changes may help you cope.

## Loss of insight or impulsive behaviour

Many people affected seem unable to understand the limitations the illness brings. As a result they can develop reckless or dangerous behaviour. In the early stages, this could be demonstrated by their insistence that they are still safe to drive despite having visual problems, poor spatial awareness and slow reactions.<sup>1</sup>

Other examples would be climbing on to chairs even though they have poor balance, or attempting to get out of bed alone when they can't stand unaided any more. Sometimes, no amount of reasoning can change this behaviour and you'll need the patience of a saint and 'eyes in the back of the head.'

## Mood Swings

Occasionally people with PSP may laugh or cry inappropriately. This can be socially embarrassing if it happens in a public place and can be distressing for you as the carer. It is important to understand that the person's reaction can be grossly exaggerated and doesn't necessarily reflect the level of emotion being felt.

### Frustration

Understandably, it is not unusual for people to get frustrated as the disease develops, especially when they can't do things like they used to. This can be down to physical limitations and increasing difficulties with communication.<sup>2</sup>

### Obsessive or repetitive behaviour

Occasionally the ability to 'switch off' an action is affected. This means that repetitive movements such as scratching or pulling at clothes, lip biting or skin picking may be seen.

If this change affects the vocal chords, then a continuous moaning sound may occur. This doesn't indicate pain or discomfort and is an involuntary action. They can't help doing it. In the few cases where this happens, it can be distressing for the carer, or disturbing to anyone present.

The person with PSP also may become mildly obsessive, for example about food or time. Management can be difficult, but distraction

<sup>1</sup> See Section "Getting About"

<sup>2</sup> See Section on Speech for advice on communication aids.

techniques usually work. These behaviours aren't harmful and may stop as suddenly as they started. Don't forget that each experience of PSP is very individual and many people won't experience any of the above symptoms. We've included them to reassure those who do.

### What can we do?

Any behavioural changes should be discussed with your GP and neurologist. Depression or low mood can be treated with antidepressant medication. These drugs not only help to elevate mood but also in some people have the additional benefit of briefly improving the symptoms of balance and speech.

Make sure the GP is aware of any difficulties at home, such as behavioural changes or if you as carer are struggling to cope. If needed, medication may be prescribed and additional support offered.

The golden rule is to accept help. Everybody needs a break, especially from a demanding and often distressing situation. Social Services can provide relief care and day centre or respite care might be available. Friends and family can help share the load both physically and emotionally. Talking about the situation will help. Feeling exhausted and resentful is a normal reaction but will not help either of you in the long run.

Do try to take each day as it comes. Some people with PSP have very little obvious change to their personality or behaviour. For those who do, many carers tell us that as time passes, the person becomes relatively calm and accepting of their situation.

**Do** remember that our PSP Nurse Specialists are on the end of the telephone to talk through any difficult problems. They fully understand you might find it difficult to cope at times and they are happy to talk to any carer who might be feeling emotional or exhausted.

<sup>2</sup>See Leaflet on Speech for advice on communication aids.



# Help & Support

Help & Support



# Going into hospital – advice for ward staff



*(Complete this and hand to ward staff on arrival)*



**NAME** .....

**Further advice is available from our team of PSP Nurse Specialists – contact details overleaf.**



## What is PSP?

Progressive Supranuclear Palsy (PSP) is a neurodegenerative disease involving the selective and progressive loss of nerve cells in certain regions of the brain, particularly in the basal ganglia and brain stem.

These areas are important for the control of eye movement, balance, speech and swallowing. They contain the substantia nigra, which is also affected in Parkinson's disease. Damage to the substantia nigra accounts for the slowness and awkwardness of movement that the two diseases have in common.

PSP can present with a wide variety of symptoms, in varying order and rates of progression. Symptoms include:

### Balance and Movement

- Frequent and unexpected falls. The falls are often backwards and can result in severe injury with fractures.
- Strategies to avoid falls and minimise their impact when they do occur should be recommended.
- Impulsive behaviour can add to the risk of falls.

### Vision

- Eye movement problems are also common. Upgaze and most characteristically downgaze, are usually affected.
- The inability to look down can lead to falls, and the inability to

see what is on the plate can lead to messy eating.

- Double or tunnel vision may occur, although the ability to focus directly ahead is usually retained.
- Slow and jerky movements can make it difficult to look from one line to the next, or one point to another.
- An inability to maintain eye contact may be misinterpreted as a sign of uninterest, which can cause communications problems.
- Involuntary closure of the eyelids (blepharospasm) can lead to functional blindness despite normal visual acuity, giving the inaccurate impression of sleep or uninterest. A dislike of bright lights (photophobia) may occur and the blink rate is also slowed, leading to soreness of the eyes.

### Speech

- Speech is often slow and slurred. It can become quieter and can have a growling quality. Repetition of words or phrases can occur.

### Swallowing

- Difficulties with feeding, eating and swallowing are common in PSP.
- Patients with PSP will probably need to be supervised when eating and drinking.
- Additional time may be needed for meals to ensure adequate nutrition.

These problems can occur for a number of different reasons at different stages of the disease because:

- The control and coordination of the mouth and throat muscles are progressively affected. Swallowing may become increasingly difficult with food going down the wrong way and entering the lungs, risking aspirational pneumonia.
- If there are associated behavioural problems, people can overfill their mouths or drink too quickly, leading to coughing or other related problems.
- Downward eye movement may be limited and hand to mouth

coordination may be difficult, resulting in messy eating or failing to absorb adequate nutrition.

## Behavioural Changes

These symptoms are due to the disease, and it's important to understand that the intelligence is largely intact.

- Apathy, irritability or frustration may occur.
- Many people become quieter and communication becomes harder.
- Mood swings may occur.

## Communication

In the later stages of PSP, communication can become extremely difficult.

This is due to a combination of symptoms:

- an increasing inability to speak
- lack of effective eye movement
- writing difficulties
- hand to eye coordination issues.

These problems can be compounded by apathy and problems with higher control of thought. Speech amplifiers, alphabet boards and light writers can help with some stages of the disease. As it progresses, though, simple communication aids, along with time and great patience from the nurse/carer are the most effective.

## Bowel and Bladder Function

Bowel control, constipation and difficulty in initiating urine flow can be common. A need to pass urine several times during the night is common.

## What is CBD?

Cortico Basal Degeneration (CBD) is closely related to PSP. It also causes disturbances of movement and behaviour and most commonly presents in people in their sixties and seventies.

It is less common than PSP, although pathologically similar, and symptom management a lot in common with that recommended for PSP.

CBD can cause the loss of use of one limb. Other early symptoms include jerking of the fingers, slowness and awkwardness of dextrous acts.

People with CBD can also have disturbances of higher sensory function and problems doing complex motor tasks, leading to difficulties in everyday activities such as cleaning their teeth, dressing and combing hair, despite having reasonably normal strength.

Unlike PSP, CBD often initially presents asymmetrically, but progressively spreads to affect the other side of the body. In common with PSP, there may be disturbance of eye movements, although it is less striking than in PSP. Paralysis of vertical eye movements is rare.

CBD patients may also have difficulties in problem solving even though memory is relatively unaffected. Depression, apathy, irritability, agitation and disinhibition can occur.

**Please complete the information below and give the completed leaflet to the ward staff**

LIST OF CURRENT MEDICATION	

	Things to think about	Describe your usual routine
Communication	<ol style="list-style-type: none"> <li>1. Do you have quiet, slow and/or slurred speech?</li> <li>2. Do you need a nurse call bell?</li> <li>3. Do you communicate using equipment/aids?</li> <li>4. Do you have problems with involuntary eyelid closure (blepharospasm)?</li> </ol>	
Mobility	<ol style="list-style-type: none"> <li>1. Do you have a tendency to fall backwards without warning?</li> <li>2. Do you use any equipment, i.e. weighted Zimmer frame?</li> <li>3. Do you require assistance when walking?</li> <li>4. Do you have difficulty looking down?</li> <li>5. Do you need a hoist for transfers?</li> </ol>	
Eating	<ol style="list-style-type: none"> <li>1. Do you have a special diet?</li> <li>2. Are there any foods you dislike?</li> <li>3. Do you need help with cutting food and eating?</li> <li>4. Do you need soft food only?</li> <li>5. Do you need special cutlery?</li> <li>6. Do you need someone to feed you?</li> <li>7. Do you have a PEG tube insitu?</li> </ol>	
Drinking	<ol style="list-style-type: none"> <li>1. Do you require a special cup or straw?</li> <li>2. Do you require drink thickeners?</li> <li>3. Do you need help with drinking?</li> <li>4. What is your preferred drink?</li> </ol>	
Sleeping	<ol style="list-style-type: none"> <li>1. What time do you go to bed and get up?</li> <li>2. Do you need help with turning in bed?</li> <li>3. Do you need assistance going to the toilet at night?</li> <li>4. How many pillows do you use?</li> </ol>	

# Useful Telephone Numbers

## PSP Nurse Specialists:

<b>Kat Haines</b>	<b>(North West &amp; Ireland)</b>	<b>01995 601533</b>
<b>Jill Lyons</b>	<b>(South West)</b>	<b>01934 842366</b>
<b>Samantha Pavey</b>	<b>(South East)</b>	<b>01747 841461</b>
<b>Katie Rigg</b>	<b>(North East &amp; Scotland)</b>	<b>01434 382564</b>
<b>PSP Association National Office</b>		<b>01327 322410</b>

**GP** **Tel:**

**Social Worker/Care Manager** **Tel:**

**Main Carer at Home** **Tel:**

## Other Contacts

**Tel:**

**Tel:**

**Tel:**

**Tel:**

**Tel:**

**Tel:**



# Information for ward nursing staff



If someone with PSP or CBD needs to be admitted to hospital, for example as a result of a fall or a problem not related to PSP, there's a good chance the ward staff won't be familiar with the disease. This means they might not know how best to help, especially if there are speech or behavioural problems.



Fill in the Advice for Ward Staff sheet in this section and hand it to the ward sister or the senior staff member on duty at the time of admission.

If communication is a problem, it's also a good idea to give staff the enclosed *Communication Advice* sheet. Make sure you give them any extra information, such as food preferences, so that the staff know a bit more about them as a person, not just a patient.



## Remember:

- **Make a list of equipment you need to take into hospital and label it clearly.**
- **Ensure you have information about PSP or CBD, and any other problems to hand.**
- **Give ward staff a current list of medications.**
- **Keep contact details of your PSP Nurse Specialist to hand for information and advice to ward staff.**
- **Have a list of people who help you at home, and their contact details.**





# Communications Advice



**A number of communication difficulties may arise due to the nature of PSP and CBD. This document has been produced by Speech and Language Therapists as an aid for hospital and care staff.**



In keeping with PSP, \_\_\_\_\_ presents with the following:

## Reduced eye and facial movements

- ✓ Due to reduced **ability to move their** eyes to follow objects or people, and possible visual disturbances, they may not be able to see you. Check that you are in their line of vision by asking if they can see you.
- ✓ If you aren't, move so that they can see you.
- ✓ Stand or sit at their **eye level**. Try to gain and maintain eye contact.
- ✓ Due to reduced eye and facial movements, it may seem that they aren't listening. Please be aware that this is not the case.



## Reduced rate and volume of speech

- ✓ They have **dysarthria**, a weakening of the muscles required for speech and swallowing. Therefore, swallowing must also be monitored by the Speech & Language Therapist. Please report any coughing or choking to your Speech Therapist immediately. This dysarthria means reduced rate and volume of speech.
- ✓ Reduce background noise. For example turn off TV, close the door or window if it's noisy outside.
- ✓ Encourage them to increase volume and project their voice if you find it difficult to hear what they are saying.

## Slowed processing abilities

- ✓ They **understand** what you are saying. However, ability to process this information and formulate a response takes a bit longer now. Please be aware of this.
- ✓ **Speak slowly.**
- ✓ Use **short, simple sentences** to help them process and remember what you're saying.
- ✓ Allow them **plenty of time** (at least half a minute, and more when tired) to process and respond. It may feel strange initially but it's only a short pause to enable them to follow and take part in conversation more easily.
- ✓ They may have **difficulty processing** more abstract information, so talk about things they're familiar with.

## Some memory difficulties and confusion at times

- ✓ They experience **memory difficulties** at times. This may mean that they forget names and part or all, of what they wanted to say.
- ✓ If they don't respond within a minute, **repeat** what you have said. Use short and simple sentences and emphasise the most important bits. Use **gestures** and ensure they can see you.
- ✓ They can be **confused** at times and this may impact on their ability to understand what you are saying.
- ✓ Say their **name or touch their hand** if you feel they have lost track of what you are saying.

## Fatigue

- ✓ They experience extreme fatigue at times, particularly from \_\_\_\_\_. Like all of us they may not feel like listening or talking when tired.
- ✓ When they are very tired, allow them to **rest**. Ask **basic questions** that need only a yes or no answer.
- ✓ Don't pretend to understand what they say when you haven't.



# Getting About



Being able to get out and about is very important. People with PSP or CBD will have to stop driving at some point, and possibly very soon after diagnosis.



Early problems may include poor spatial awareness, poor driving judgement and becoming confused about traffic rules or navigation. Address this issue earlier rather than later, for everyone's safety.

## Reporting



Taking the decision to stop driving is not for the person with PSP or the carer to make. After diagnosis, the DVLA must be notified as soon as possible. Not to do so is a criminal offence. You can contact DVLA via:

Address: Drivers Medical Group, DVLA, Swansea SA99 1TU

E-mail: [eftd@dvla.gsi.gov.uk](mailto:eftd@dvla.gsi.gov.uk)

Telephone: 0300 790 6806

Textphone: 0300 123 1278

Fax: 0845 850 0095

## Assessment

Reporting the diagnosis to the DVLA does not mean the person's driving licence will be withdrawn immediately. The DVLA will conduct an assessment from the information that you and your doctors provide, or they may request attendance at an assessment centre before making a decision.

## The Options

There are essentially four ways for the person with PSP to maintain the ability to travel further afield:

- **Car Accessories**

If getting in and out of the car becomes difficult, accessories are available to help people who have some ability to stand or to help the carer move them. For example:

Small turntables can be placed on the car seat or on the ground to help turn the person around into a normal car seat. These are fine for short journeys (10 -15 minutes' duration) but aren't recommended on long journeys as the padding is insufficient.

Car roof-mounted hoists to transfer from car seat to wheelchair, although they can be slow and cumbersome. It might be better to consider acquiring an adapted vehicle (see below for more information).

- **Local Transport Schemes**

Some areas operate social car schemes using volunteer drivers. To find out what is available in your area contact:

**The Community Transport Association:**

0845 130 6195 or [www.ctauk.org](http://www.ctauk.org) (UK)

049 432 3849 or [info@communitytransprt.ie](mailto:info@communitytransprt.ie) (Republic of Ireland)

**The Women's Royal Voluntary Service (WRVS):**

029 2073 9000 or [www.wrvs.org.uk/contact-us](http://www.wrvs.org.uk/contact-us)

**St John's Ambulance:**

08700 104 950 or [www.sja.org.uk](http://www.sja.org.uk)

**British Red Cross:**

Number in your phone book, or [www.redcross.org.uk/yourarea](http://www.redcross.org.uk/yourarea)

**Door to Door:**

The Disabled Persons Transport Advisory Committee (DPTAC), provides advice to disabled people about travel using all forms of transport. [www.dptac.gov.uk/door-to-door](http://www.dptac.gov.uk/door-to-door)

## Shopmobility

Loan or hire of wheelchairs and scooters at shopping centres. You usually park right next to the office in a multi-story car park and go from there.

08456 442 446 or [www.shopmobilityuk.org](http://www.shopmobilityuk.org)

## Powered Scooters

Battery powered scooters are useful for short distances and are easy to get on and off. However, you will need somewhere to store and charge them and they're designed for use on a road or a paved surface so rarely offer a means of getting round inside the home or many shops. They're also expensive, so the long-term benefit should be weighed carefully against the cost. We recommend that you discuss individual symptoms and likely benefits with your Occupational Therapist before making any commitment.

### Car or Van Adaptations

The best longer-term solution for those with PSP or CBD is likely to be a specially adapted vehicle to carry manual or powered wheelchairs

**The rest of this section looks at helping you make the right decision for you.**

## Motability

If you are receiving the Disability Living Allowance Mobility component at the Higher rate (as long as it is an indefinite award or has at least 12 months to run) or the War Pensioner's Mobility Supplement, then you can access Motability.

You can use Motability to fund the hire or hire-purchase of a vehicle, adapted vehicle, scooter or powered wheelchair. The rates offer VAT exemption and include insurance, servicing, repairs and breakdown cover.

Contact: 0845 456 4566 or [www.motability.co.uk](http://www.motability.co.uk) for more information.

A few wheelchair-converted vehicles, such as those based on Renault Kangoo and Peugeot Berlingo have zero advance payment, but many

conversions require a lump sum at the beginning of the five-year contract through Motability. There is generally no funding for this and at the end of five years, you hand the vehicle back without refund of that payment.

You can have a normal car on Motability without conversion but they will have to approve any changes you might make to the car such as swivel seats. These usually have to be removable at the end of the term.

## Vehicles Adapted for Wheelchairs

### Advice

Expert advice is essential, and your first step should be to contact a source such as an accredited member of the Forum of Mobility Centres. Your nearest centre can be found by calling 0800 559 3636 or on [www.mobility-centres.org.uk](http://www.mobility-centres.org.uk).

### Solutions

A wide variety of solutions is available, including:

- **Ramp Access**

Many options have ramp access, usually from the rear, for the wheelchair to be driven or pushed into the vehicle. (Powered lifts are available, but simple ramp access is often adequate.) The chair is clamped to the vehicle and the occupant provided with an inertia reel seat belt. The loading and unloading process can be quite rapid, and doesn't need a carer with much strength or agility.

Depending on the size of the vehicle, seats for three other passengers are available in most conversions. Another important point to consider is the view out of the vehicle for the wheelchair occupant. Some conversions provide windows at head height, providing a near-normal view out of the vehicle, but others don't. Consider carefully whether being transported at speed in a metal box, with little view of the world outside, would be an enjoyable experience!

- **Front Seat Systems**

The front passenger seat is replaced with a seat that swivels out of the vehicle and lowers to a height permitting easier transfer of the wheelchair occupant into the car seat.

However, this solution does need a relatively active carer to handle the transfer as well as the stowage of the wheelchair.

- **Integral Front Seat and Wheelchair Systems**

This involves the removal of the front passenger seat and its replacement by a set of rails on a lockable turntable. This goes with a wheelchair that has the seat mounted on similar rails. The rails in the car and the chair are lined up. The chair is then slid into the car, locked and turned to face forwards. The wheelchair base is then placed in the car boot.

This offers a better passenger experience for the wheelchair user and makes it easier for the driver to talk to the passenger. Like the simple front seat systems, it needs an active carer (and a reasonable sized boot) to assist.

Conversions can be expensive even though they are zero-VAT rated. For example, a wheelchair system with a removable base that is stored in the boot may cost around £5,000. Motorised versions, where the seat folds underneath the chair could be around £12,000.

There are several companies providing vehicles adapted to carry wheelchairs. They supply new or second-hand vehicles and carry out conversions. Many will drive the vehicle to your house for a no-obligation demonstration. The PSP Association does not specifically recommend any company, but some contacts to obtain brochures and price lists are:

Atlas Conversions	<a href="http://www.atlasconversions.co.uk">www.atlasconversions.co.uk</a>	02392 265 600
Brotherwoods	<a href="http://www.brotherwood.com">www.brotherwood.com</a>	01935 872 603
G F Clarke	<a href="http://www.gfclarke.com">www.gfclarke.com</a>	01622 793 079
PB Conversions	<a href="http://www.pbconversions.co.uk">www.pbconversions.co.uk</a>	01525 850588
The Wheelchair Accessible Motor Company Limited	<a href="http://www.twamco.co.uk">www.twamco.co.uk</a>	01215 508 844
Constables Mobility	<a href="http://www.constablesmobility.com">www.constablesmobility.com</a>	01323 767 574

Other useful organisations or publications if you're considering a second-hand vehicle are:

Mobilise [www.ddmc.org.uk](http://www.ddmc.org.uk) or 01508 489 449, who also offer a range of discounts for parking, ferries, and equipment.

Exchange and Mart (see section on Adapted Vehicles.)



# Transport



If you're caring for someone with PSP or CBD, you may find that they are entitled to some, or all of the following:



## Blue Badge Scheme

Your Local Authority issues these. They offer the use of disabled parking bays and many other parking concessions. Some cities, including London, operate their own schemes, so check locally.

PSP and CBD patients are likely to qualify if they:

- Receive the DLA Higher Rate Mobility Component or
- Are assessed as having a 'permanent and substantial difficulty to walk or very considerable difficulty in walking.' It's worth checking with your GP before submitting the form.



## Exemption from Vehicle Excise Duty

For further information visit [www.direct.gov.uk/](http://www.direct.gov.uk/) (motor and transport section) or call 0845 712 3456

## Disabled Person's Railcard

This offers a third off most fares. People with PSP and CBD should qualify if they receive AA or DLA Care or Mobility Components at Middle or Higher Rates or are registered as visually impaired.

## Bus Discounts

Your Social Services department will advise on any local Bus discounts available.

## Ferries. Toll Roads. Tunnels and Bridges

Many operators offer discounts and toll exemptions. Contact either:

- The Disabled Drivers Motor Club: Cottingham Way, Thrapston, Northants NN14 4PL (01832 734 724) or
- The Disabled Motorists Federation: CVS Volunteer Centre, Chester-le-Street, Co. Durham DH3 3DQ (0191 4163172)

## Health Benefits

### Prescription Charges

People with PSP or CBD will be automatically exempt from prescription charges if:

- They are over 60 or
- Receiving Income Support
- Receiving ESA (Income- Related)
- Receiving Pension Credit Guarantee Credit.

If not, you will need to apply for an Exemption Certificate from your GP.

### Sight

People with PSP and CBD may qualify for free eye tests and vouchers towards the cost of glasses or contact lenses. Ask for the voucher at the time of the test. They may qualify if they:

- Are receiving Pension Credit, Guarantee Credit, Income Support or ESA (Income- Related).
- Are on a Low Income. The criteria for deciding Low Income is similar to, but not the same as, those for Income Support.
- Need complex or powerful lenses.
- In any event, you qualify for free eyesight tests if you are over 60 or registered as partially sighted.

If you have a certificate from an ophthalmologist stating you are blind or partially sighted, you will be entitled to receive free Talking Books and Newspapers. (See section on Sight.)

## Travel to Hospital

People with PSP and CBD, along with you as carer, might be able to claim a refund of fares to and from hospital.

The refund would be up to the cost of a standard fare by public transport or a taxi fare if public transport is not available or not possible due to the disability. Ideally, agree travel costs in advance. You may be eligible if the person gets:

- Income Support, Pension Credit, Guarantee Credit or ESA (Income-Related).
- Are on a Low Income (see “Sight” above).
- Are resident in a care home and at least part funded by the Local Authority.





# Work, Benefits and Finance



This section indicates areas where you might be eligible to receive financial support if someone you care for has recently been diagnosed with PSP or CBD, and how to go about obtaining it. Here we aim to cover

- Help with Staying in Work
- State Benefits paid by the Department of Work and Pensions
- Local Authority Benefits and Support
- Other Financial Support including NHS and Transport Concessions
- VAT Relief
- Charitable Help



Please note that this section doesn't provide an authoritative statement of entitlement or transitional entitlements to benefits.

The person with PSP has probably contributed to the running of this country for most of their life, so don't feel at all embarrassed about getting all available support. It's important to understand entitlements and how to progress claims.

Sometimes the number of forms can seem overwhelming and the process isn't helped by the varying assessment standards and availability of support. However, it is not all bad news because:

- Once you're 'in the system' then things become a lot easier
- There's a lot of help available to assist you
- Many of the forms consist of 'tick' boxes and aren't as daunting as you might think

## Advice

If your request or claim is rejected, there's usually an Appeals process at which many PSP and CBD patients are successful. However, it's best to make a complete and convincing initial submission. There's plenty of local advice available, including:

- Your local branch of Carers UK. Call 0207 490 8818 or visit [www.carersuk.org](http://www.carersuk.org) to find your nearest.
- Your nearest Citizen's Advice Bureau – [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)
- Your local branch of Age UK – [www.ageuk.org.uk](http://www.ageuk.org.uk)
- Other PSP and CBD carers, if you have joined our local telephone contact network or are able to attend your nearest PSP Support Group
- The various Government Helplines, stated on the application forms
- The Disability Rights Handbook. Published by the Disability Alliance 020 7247 8776, [www.disabilityalliance.org](http://www.disabilityalliance.org)

### Staying in Work

An early diagnosis of PSP or CBD does not mean that the person you're caring for will have to stop working immediately. At the same time, it's better to be realistic about what you, whether as patient or carer, will be able to continue doing.

It is important to discuss the future with your employer sooner rather than later. There may well be alternatives in terms of work area, working hours or job content.

The Disablement Recruitment Officer or Disability Employment Adviser at your local Job Centre Plus can advise on benefits. They should also be able to offer advice and financial support for any adaptations at work you may need through the 'Access to Work' scheme, including:

- Any special aids or adaptations needed for employment
- Adaptations to premises
- Help with travel to and from work
- A support worker to provide help in the workplace
- A communicator for job interviews

The Access to Work scheme should usually cover 80%, and in some cases up to 100% of the costs, although you may be liable for the first £300.

## State Benefits

The Department of Work and Pensions (DWP) system can seem complex, but it falls into the four categories below. The most relevant benefits for PSP and CBD patients and carers are highlighted in **bold**:

- **Contributory**

These are intended to compensate people who don't work, for their loss of earnings. Entitlement depends on National Insurance (NI) contributions and only one of these benefits (or Carers Allowance - see below) is payable at any one time. It is therefore sensible to apply for the benefit offering the highest rate although any additions over the appropriate basic rate may still be received:

- State Retirement Pension
- **Employment and Support Allowance (Contributory element)**
- Jobseekers Allowance (Contribution-based)

- **Non-Contributory**

Entitlement depends on meeting certain conditions, but they're not means-tested or dependent on past NI contributions. They're intended to help people with the extra costs incurred by their circumstances:

- **Carers Allowance** (although other income is taken into account.)
- **Disability Living Allowance**
- **Attendance Allowance**
- Industrial Injuries Benefit
- War Disablement pensions and Armed Forces compensation scheme
- Category D Retirement Pension (for those over 80)

- **Means-Tested**

Paid to people whose income and their partner's income, and/or capital, is below a certain level. They can be paid on their own, or can "top-up" contributory, non-contributory or employee benefits.

- Income Support

- **Employment and Support Allowance (Income Related)**
  - **Pension Credit**
  - Jobseeker's Allowance (Income-based)
  - The Social Fund
  - Working Tax Credit (through the Inland Revenue, not the DWP)
- **Employee-Based**
    - Statutory Sick Pay

## Main benefits relevant to PSP and CBD

A diagnosis of PSP or CBD may mean entitlement to some of the benefits highlighted in **bold** above:-

- Employment and Support Allowance (ESA)
 

*(If you can't work and have not reached State Retirement Age. It is paid in two parts: based on National Insurance contributions, and a means test)*
- Carers Allowance (CA)
 

*(If you care for someone for more than 35 hours a week)*
- Disability Living Allowance (DLA)
 

*(If you are disabled and apply before you reach 65)*
- Attendance Allowance (AA)
 

*(If you are disabled and apply when you are over 65)*
- Pension Credit (PC)
 

*(To increase your income to a certain level if you are over 60)*

# Local Authority Benefits and Support

## The Needs Assessment

People with PSP or CBD are legally entitled to a Needs Assessment by the Local Authority. Your GP will give you the appropriate Social Services contact. However, most Local Authorities are now working much more closely with the NHS and you should follow the pathway detailed in the section 'Continuing Care.'

Help identified in the Needs Assessment as Health Care is provided by the NHS free of charge, but help defined as Social Care is provided by the Local Authority and is usually means-tested.

## Other Financial Help

You may also be entitled to one or more of the following types of financial help from your local authority. See the section 'Getting Help.'

- Council Tax Reductions - due to your disability
- Council Tax Benefit - means-tested if you have difficulty paying
- Housing Benefit - means-tested if you have difficulty paying your rent
- Housing Adaptations and Equipment - due to your disability, although they may be means-tested

## Other Financial Support

You may be entitled to many other discounts or exemptions. The main ones that may be affected by a diagnosis of PSP or CBD are:

### Transport

- See the section 'Transport'

### Health Benefits.

You may be entitled to:

- Be exempt from Prescription Charges
- Free Eye Tests and Free or Subsidised Glasses or Contact Lenses
- Free Talking Books and Newspapers. See section 'Sight' for more details.

## VAT Relief

People with PSP shouldn't have to pay VAT on equipment or services related to their disability, including:

- Disability aids including lifts, adjustable beds, bathing and toileting aids.
- A vehicle modified to carry a wheelchair
- Home adaptations to help with their disability, including the provision of a downstairs bathroom. However, the provision of, for example, an extra bedroom downstairs would be unlikely to qualify as it would be seen as a home improvement.
- Most repairs to equipment for the disabled.

## Charitable Support

Many local and national charities offer support. Some are open to everyone, others are nationality-based or established to support people with a certain professional, trade or faith background. Useful sources of information include:

- Turn2us ([www.turn2us.org.uk](http://www.turn2us.org.uk)) or 0207 396 6700, who provide a very comprehensive list of charity help available
- Agencies listed under 'Advice' at the beginning of this section
- Lions Club International ([www.lions.org.uk](http://www.lions.org.uk)) or 0121 441 4544
- National Association of Round Table [www.roundtable.co.uk](http://www.roundtable.co.uk) or 0121 456 4402
- Rotary Club International [www.ribi.org](http://www.ribi.org) or 01789 756 411
- If you, your spouse, or your ex-spouse were ever a member of HM Forces, then it would be worth contacting the relevant service charity, such as your local branch of SSAFA, the British Legion, the Officers' Association, the Royal Navy Benevolent Fund, your Regimental Association or the RAF Benevolent Fund.



# Benefits – Further Information



## When completing forms...

- Be realistic rather than optimistic.
- Don't say the person can do something when in reality it causes them pain or exhaustion.
- Focus on their worst day and fill in the form on that basis – that's when they need the help.
- Try to give a clear picture of the situation. For example, if the question is: 'Can the person wash and dress?' don't just say 'Yes' if the real answer is 'It takes him two hours with frequent rests and he needs someone to help with fastenings.'
- To make a successful claim it's worth seeking experienced help. You might want to consult your GP, OT or Physio before submitting a claim. They might also be willing to write an assessment report for you.
- Keep a copy of your submission handy as the authorities often phone to confirm details and it is important that what you say on the phone is the same as in the application.
- It may help to keep a diary of activity, to have something to refer to.

## Disability Living Allowance (DLA)

### Rates

There are two parts to the benefit: a Care component and a Mobility component. DLA is tax-free.

- The disability will need to have existed for 3 months before claiming. Keeping a diary of the likely help required would be useful in support of the claim. If the applicant is assessed as terminally ill (see below) then there is no prior qualification period

## Eligibility

Claims must be made before the person's 65<sup>th</sup> Birthday, although payments will then continue afterwards. Examples include:

- **Care Component Lower Rate.**  
If help is needed with bodily functions for a significant part of the day *or* with cooking: assembling implements and reading recipes
- **Care Component Medium Rate.**  
If frequent help is needed with bodily functions during the day *or*
  - Prolonged or Repeated attention during the night *or*
  - Continual supervision from another person during the day to avoid danger *or*
  - Supervision for prolonged periods or frequent intervals during the night to avoid danger
- **Care Component Higher Rate.** You may be eligible if you:
  - Meet the Medium Rate conditions for attention or supervision for both day and night.
  - Are terminally ill, defined as:
    - Having a progressive disease (such as PSP or CBD) *and*
    - Your death can be reasonably expected within 6 months. The key phrase here is 'can be reasonably expected', which is not the same as 'will occur'. You should talk to your GP if you want to claim Higher Rate just for this reason
- **Mobility Component Higher Rate** may be paid if you are unable or virtually unable to walk. Decisions are based on the restrictions on the speed, distance, time and manner of walking outdoors on level ground. Key issues for PSP and CBD patients might be:
  - The distance that can be achieved without the risk of falling due to balance or vision problems
  - The distance that can be achieved without pain or breathlessness
  - If you're granted Mobility Component Higher Rate, you can apply for exemption from Vehicle Excise Duty (Road Tax)

provided that the vehicle is solely for the person affected's use or for their purposes.

- **Mobility** Component **Lower** Rate may be paid if they need guidance or supervision when using unfamiliar routes outdoors.

### Definitions

Each application is viewed individually, but the following general definitions may help:

Attention:	Personal contact or intervention i.e. physical help.
Bodily functions:	Includes eating or drinking, toileting, seeing, hearing, communicating, thinking or dressing, getting in or out of bed.
Continual:	At least at beginning, middle and end of the day
Frequent:	At least 3 times a day
Guidance:	Need help to find your way around outdoors on an unfamiliar route.
Prolonged:	More than 20 mins per session
Repeated:	More than once
Significant:	Typically at least 30 mins per day, but could be less (reminders to take medicine?)

### Notes

- If you can, it is important to claim DLA before you reach age 65 as your entitlement to DLA will then continue past that point. If you claim after age 65, you will be offered Attendance Allowance instead which offers similar benefits to Middle and Higher Rate Component DLA, but significantly does not offer any Mobility component.
- Getting the middle or highest rate of the care component may mean that you, as carer, qualify for Carers Allowance.
- Getting the higher rate of the mobility component can mean that the person you look after can get a blue badge for their car from Social Services and exemption from road tax from the Disability Benefits Unit. Call them on 0845 712 3456.

- If you get Disability Living Allowance, you may qualify for more Income Support, Pension Credit, Housing Benefit or Council Tax Benefit (called 'Rate Rebate' in Northern Ireland).

### How to Claim

Call the Department of Work and Pensions enquiry line for carers and disabled people on 0800 882200.

## Attendance Allowance (AA)

### Rates

There are 2 rates: *Higher and Lower*. AA is tax-free.

#### Eligibility

The criteria for Higher Rate AA are similar to those used for the **Care Component Higher** Rate DLA.

The criteria used for Lower rate AA are similar to those used for **Care Component Medium** Rate DLA).

The disability will need to have existed for 6 months before claiming. Keeping a diary of the help you need would be useful in support of the claim. If the person with PSP is assessed as terminally ill (see page xx) then there is no prior qualification period.

### Notes:

- See notes and definitions for DLA
- Getting the benefit can also mean you receive extra Pension Credit, Housing Benefit and Council Tax Benefit.
- Getting this benefit may mean that your carer can apply for Carer's Allowance.

### How to Claim

Call 0800 882 200 and ask for the form DS2.

## Carer's Allowance (CA)

Claims can be backdated for up to three months, but once claimed, there are allowances made for respite or other breaks.

An additional sum may also be paid for a dependant partner, but cannot be paid if the partner's earnings, non-means-tested benefits or private pension equals or exceeds that amount.

CA is taxable.

### Eligibility

- You must be 16 or over and not a full time student.
- You care for one person for at least 35 hours each week including any travel from your home to the place of caring, and sleeping while caring. Claims for weeks less than 35 hrs (Sun to Sat) cannot be 'topped up' from other weeks of more than 35 hours caring.
- The person you look after must be severely disabled (as defined on the application).
- You can claim CA even if you are receiving AA or DLA in your own right but you must then be caring for someone receiving AA, or DLA Care Component at Medium or Higher Rate.
- You are the only claimant for the person you are caring for.
- If you work, you must not earn more than a certain amount each week. Check [www.direct.gov.uk](http://www.direct.gov.uk) for the latest details.
- You must be living in the UK when you claim Carer's Allowance, and for 26 of the last 52 weeks.

### Notes

- You may also be able to get the Carer Premium - an extra amount of money included in the calculation of Employment and Support Allowance, Income Support, Income-based Job Seekers' Allowance, Housing Benefit and Council Tax Benefit (Rent Rebate in Northern Ireland). An amount equivalent to the Carer Premium is used to calculate Pension Credit.

- It may therefore be worth claiming Carer's Allowance even if you are denied it because you are receiving a State Retirement Pension, for example. However, if you are paid CA, the person you are caring for cannot get the Severe Disability premium (£52.85 per week) included in their Means tested benefits.

### How to Claim

Complete claim pack DS700, obtainable from your local Social Security office or the Benefits Enquiry Line on 0800 882 200 (or 0800 220 674 in NI), or online from [www.direct.gov.uk](http://www.direct.gov.uk) (not in NI)

## Employment and Support Allowance (ESA)

ESA is paid to people who can prove that they have a limited ability to work due to ill health or physical disability. There are two types of ESA:

### Contribution-based ESA(C)

It is not means-tested and eligibility depends on your record of recent National Insurance Contributions.

### Income-Related ESA(IR)

Aimed at topping up income to a level that Parliament has decided is enough to live on. That level is likely to be higher if you suffer from, or care for someone suffering from, PSP or CBD. ESA(IR) can be paid on its own, or used to top up ESA(C). It is means tested.

When you claim, you will enter a 13-week Assessment Phase. This will determine if you are entitled to ESA and if so, whether you join the 'Support Group' or the 'Work-related Activity Group.' (WRAG)

If accepted for ESA, work-focused interviews will then be available. The main difference between the Groups is that the interviews are mandatory for the WRAG and optional for the Support Group. **If you are in the WRAG and fail to take an active part in the interview process without good cause, your ESA will be halved for the first 4 weeks and then stopped.**

If you receive ESA(IR), you may also be entitled to housing and council tax benefit and will not have to undergo a separate assessment.

### For further information...

Contact Job Centre Plus on 0800 0556 688 or face-to-face through most Job Centres. If you fail the assessment, you can **appeal** – and still be paid at the Assessment rate until the appeal is decided.

## Pension Credit (PC)

### What is it?

Like Income Support (IS), PC may be payable if earnings and savings are below a certain level. That level is established by calculating the sum of the person's:

- Guarantee Credit
- Savings Credit if they or their partner are over 65.

### Eligibility

- Over 60.
- Only one member of a couple may claim (although one can be under 60.)
- Must meet certain GB residency requirements.

**The Guarantee Credit** consists of a Standard Minimum Guarantee with additional amounts paid for things like severe disability. Check **[www.direct.gov.uk](http://www.direct.gov.uk)** for latest rates and more details.

People receiving PC are entitled to other benefits, including:

- Free prescriptions and dental treatment
- Housing Grants
- Help from the Social Fund
- Help with hospital fares
- Help with Energy Efficiency Grants

### How to Claim

Contact the Pensions Service on 0800 99 1234 (or 0800 100 6165 in

Northern Ireland). The Pensions Service will complete the claim for you over the phone and send it to you to check, sign and return.

## Local Authority Benefits

Here we cover the following Local Authority Benefits:

- Council Tax Reductions
- Disability Reduction
- Discount Scheme
- Council Tax Benefit
- Housing Benefit (HB)
- Housing Adaptations and Equipment.

*It is important to note that this is only a general and approximate outline of entitlement. The full rules can be complex and should be individually checked. The PSP Association cannot be held liable for the accuracy of the information provided.*

## Council Tax Reductions

You may be entitled to 2 types of reduction: a Disability Reduction and/or a reduction under the Discount Scheme. These can be backdated to the point that they became justified.

### Disability Reduction (DR)

The DR will reduce your Council Tax to the next lower Banding for your property. You may qualify if:

- You have an additional bathroom, toilet or kitchen for the sole use of the PSP or CBD patient.
- You have another room for the sole or main use of the patient. This could include a downstairs bedroom or a room mainly used to store and charge an electric wheelchair.
- You have enough space to use a wheelchair indoors.

Guidance to local authorities suggests that the test is to consider how difficult life would be for the patient if that facility wasn't available.

### Discount Scheme (DS)

Council Tax is based on the number of residents: 100% is due if there is more than one resident and 75% is due if only one resident. Resident carers can be counted as 'invisible' for Council Tax purposes if he/she/they:

- Provide care for at least 35 hours a week, and the carer is not the spouse or partner of the patient and the patient is entitled to DLA Care Component or AA at the highest rate. You do not have to claim Carer's Allowance to qualify and more than one carer could claim.
- Provide care for at least 24 hours a week and are paid no more than £44 and the carer has been provided or introduced by the local authority, NHS or a charity.

### Council Tax Benefit

You may be entitled to help with your Council Tax (or help with Rates in Northern Ireland) if:

- You are on Income Support, Employment & Support Allowance (Income-Related) or on a low income.
- Your capital does not exceed a certain level.

### Housing Benefit (HB)

You may be entitled to HB if:

- You are paying rent on a commercial basis.
- You are on Income Support, Employment & Support Allowance (Income-Related) or on a low income.
- Your capital does not exceed a certain level.

## Housing Adaptations and Equipment

The owner, tenant or landlord can apply for financial help with housing adaptations and equipment. Maximum limits can be up to the order of £20,000 and £30,000, depending on where you live:

- England, Wales and Northern Ireland: Your Local Authority has discretionary powers to help and you should ask for a copy of its policy. Equipment and minor adaptations up to £1000 should be provided free of charge in England. In Wales, Local Authorities aim to provide equipment to the value of £350 within 15 days.
- Bigger grants (or in some cases loans) may be means-tested, but the capital and income thresholds will usually be much higher than those used to assess Income Support or Pension Credit, so you should always investigate what help is available in your area.
- Scotland. The Scottish Executive booklet *Housing Grants* will be available from your Local Authority and it defines the assistance you can expect to receive. In broad terms, the Local Authority should meet at least 80% of the cost of providing bathing, washing and toileting adaptations, and meet all of the costs if you have a low income and receive certain State Benefits.

Note that even if you have to fund the adaptations yourself, your Occupational Therapist (OT) should offer advice, and you should be able to claim VAT exemption on the work and materials.



# Support for Carers



Looking after someone with PSP can be demanding. If you're just starting out on this journey, now's the time to lay foundations that'll make it easier for both of you in the long run.



If you've already been caring for some time, it's important to look after yourself as well. The reality is that you're caring twice over – for both of you!

Let's look at how some of this can be achieved.

## Practical Help



### Carers Assessment

Everyone in a caring role is entitled to a Carers Assessment from Local Authority Social Services. The aim of this is twofold:

- to discuss any assistance you might need with caring
- and to maintain your own health so that you can balance caring with other work and family commitments.

Even if you suspect that you might have to pay for whatever assistance is identified, it's well worth having a Carers Assessment to ensure that you are 'in the system' and should receive sources of information and practical support.

Carers UK publish a good Carers Assessment Guide, available at: [www.carersuk.org](http://www.carersuk.org).

If you don't have internet access, find someone who has or ask your local library to download the information for you. Alternatively, call the CarersLine on:

0808 808 7777 Wed/Thurs only or 020 7922 8000 at other times.

As circumstances change, apply for another assessment.

## Your GP

Tell your GP that you're a carer. The Government requires surgeries to have a register of carers and you should get priority when arranging appointments.

Consider asking your GP to arrange a physiotherapist to train you to lift without injuring yourself. Your back may well be a critical part of your caring toolbox and it needs protecting!

The Government offers 'Carers Direct' within NHS Choices at [www.nhs.uk/carers](http://www.nhs.uk/carers) with helpful information on assessments, wellbeing, financial and legal aspects. If you don't have internet access, call the helpline: 0808 802 0202 or email [CarersDirect@nhschoices.nhs.uk](mailto:CarersDirect@nhschoices.nhs.uk) for free, confidential advice.

## Financial Help

You may be entitled to Carers Allowance and Carers Premium – see our section Work, Benefits and Finance. If you're working and also caring, you have statutory rights for flexible working under the Work and Families Act 2007. Ensure you let your employer know about your caring responsibilities.

Carers UK have some very useful leaflets to download on [www.carersuk.org](http://www.carersuk.org)

## Road Tax Exemption

If the person you're caring for gets the higher rate mobility element of Disability Living Allowance, they should be exempt from paying road tax. If they don't drive but you do, you can be nominated to get the exemption in their place. Contact the Disability Living Allowance Unit and ask for exemption certificate DLA 404 – Tel. 0845 712 3456.

## Respite Care

Being a carer can be physically and emotionally exhausting and respite may become vital to you. There are many types of respite available – choose what suits you and gives you some space to yourself.

Some local authorities offer Direct Payments or even Vouchers that can be used very flexibly to suit your situation – see the Department of Health website [www.dh.gov.uk/](http://www.dh.gov.uk/) for details.

### Brief Respite

For brief respite of a few hours or even a day - consider Day Care Centres in your area. Details are available through Social Services and/or your GP.

Many carers find 'sitter' services useful. Your local Social Services should be able to provide advice, or contact Crossroads at:

[www.crossroads.org.uk](http://www.crossroads.org.uk) or call 0845 4500350 to find your local branch.

Friends and family will often be happy to help out for a few hours and remember that the person with PSP may well enjoy a change of social scene! Don't be nervous about asking for help from friends rather than struggling on alone.

### Longer Periods

For extended respite, look for a care home that can provide suitable services for short stays. This may or may not be funded by Social Services depending on the type of care package you are able to access.

Care home staff will need to understand the demands of the disease, especially if there are speech, behavioural or falling problems. Try to make an appointment to speak to staff who will be directly involved and provide them with copies of the relevant leaflets from this pack, including a completed copy of the 'Into Hospital' leaflet.

Give them the number of your PSP Nurse Specialist. If you have any specific worries, it might be a good idea to ask your PSP Nurse Specialist to contact the home before admission.

Another option is to get a member of your family to 'live in' while you take a break. This has the added advantage of educating the family about the complexities of being the 'main carer' in a family!

It's also worth considering nearby hospices for a short stay. Approach

them direct, or obtain a referral from your GP. As yet, there is no national list of hospices offering services for people with neurological conditions, but you can find where your nearest hospice is by contacting Hospice Information:

[www.hospiceinformation.info/findahospice.asp/](http://www.hospiceinformation.info/findahospice.asp/) and then click on relevant country tab or call 0870 903 3903.

Don't be put off by the tag 'hospice' - it is not a last port of call but a specialised service for those with complex conditions.

It's a good idea to plan respite breaks into your calendar on a regular basis - this gives you something to look forward to and becomes part of the care routine. The earlier you set this up, the easier it is for both of you.

## Use the support around you

### Establish a Support Network

Consider establishing a strong network of people around you - your family, friends and any others who can help if times get tough.

Many local authorities provide Carer support groups and your GP surgery can give you details. Apart from being able to meet others facing similar challenges, other members will know where to find the best practical local help.

In the UK, try The Princess Royal Trust for Carers who facilitate many Carers Centres around the country - [www.princessroyaltrust.org.uk](http://www.princessroyaltrust.org.uk)

You could also contact Carers UK [www.carersuk.org](http://www.carersuk.org)

It's worth subscribing to Carers UK. Their regular magazine will keep you up to date with the many initiatives within the caring community.

Membership Hotline – 020 7566 7602

Alternatively, call the CarersLine on 0808 808 7777 Wed/Thurs only or 020 7922 8000 at other times.

Don't dismiss the idea of counselling - it can be very useful to have someone unconnected to talk through difficult feelings and tensions that can arise when caring for someone. Ask your GP to arrange this.

## The PSP Association

Remember that our Specialist Nurses are available to talk - for advice or just to bounce ideas off!

There's also a PSP Forum on our website [www.pspeur.org](http://www.pspeur.org) and social networking site, Health Unlocked, <http://psp.healthunlocked.com/> where you can pick up lots of ideas from other carers and get (and give) peer support.

You're also most welcome at the many support group meetings throughout the country. Making time to get to these meetings is a useful way of establishing 'time off' and setting up your carer network to enable you to attend. It also gives you a chance to meet other PSP carers.

Above all - remember you're not alone - there are many ways to get help and support - you only have to ask





# Complementary Therapies



## Overview

We're often asked about the use and possible benefits of complementary therapies for PSP and CBD. While we have no evidence that any complementary therapy can modify the duration of either condition, some people tell us that the use of therapy has helped to alleviate symptoms and may therefore be well worth considering.

Most complementary therapies, as the name implies, 'complement' rather than replace modern medicine, and some are becoming more available in mainstream medical establishments.

Before embarking on any complementary therapy discuss it with the GP and /or Consultant to ensure that there will be no likely adverse affect with any current treatment the person you're caring for is receiving.

Complementary therapies are increasingly recognised by the NHS. Many GP practices now provide their own complementary therapy service or can refer you to local appropriately qualified therapists. Most therapies still need to be paid for privately, by the individual, so you should check with your GP.

## What Might Help?

Complementary therapy offers a different approach to more traditional methods – usually involving the body, mind and spirit. This holistic approach may, for some, lead to feeling 'more in control' of the situation.

It's generally thought that relaxation can help to reduce anxiety and stress, which can be brought on by many of the problems associated with everyday living for people with PSP/CBD and their carers. Complementary therapies may provide some people with relief from symptoms associated with:

- Tension/Stress
- Anxiety/panic attacks



- Depression
- Pain
- Musculoskeletal problems
- Breathlessness
- Constipation
- Temperature control
- Sleeplessness/fatigue

### Finding a Therapist

Care should be taken to find a reliable therapist, preferably one who is recommended by and connected to a recognised authenticating and regulatory body. Any therapist dealing with a PSP patient will need an understanding of the disease and any other conditions the person with PSP might be experiencing.

The therapist must be made aware that PSP is both progressive and neurological. The first session will involve the therapist learning about the patient and the illness and then determining whether they will be able to help.

Take this Carer's Guide with you to give them more information or direct them to our website – [www.pspeur.org](http://www.pspeur.org). The therapist will also need to know how the illness is affecting the client. This must be the prelude to any useful treatment.

Therapists should have a basic understanding of the clinical issues with which they may be faced when providing therapy to someone with PSP/CBD. These may include:

- Problems with speech and communication

- Fatigue
- PEG feeding (feeding through a tube into the stomach)
- Breathing problems (*please note: some essential oils have contra-indications for respiratory dysfunction*)
- Muscle spasms
- Muscle weakness
- Altered posture
- Impaired use of legs, arms and hands
- Pain

Therapists should also be aware of any medication being taken by someone with PSP/CBD, to avoid conflicts with the therapy they may be providing.

### Questions to ask before treatment

- Is there information about the therapist, the practice and the treatment that you can read in advance? This should give details of the therapist's training, qualifications, membership of organisations, and how long they have been practising. This information should also explain how the treatment works. If not – ask!
- How much does it cost? Beware of paying for a number of sessions in advance. You should be able to pay for one session at a time.
- Is a record of the treatment kept?
- Is the place of treatment accessible?
- Are there any preparations you should make before attending?
- Have they treated people with long-term conditions before?
- Are they insured if anything goes wrong?

This site may be useful if you are worried about a therapist being genuine: [www.quackwatch.org](http://www.quackwatch.org)

## Possible Complementary Therapies for People with PSP or CBD

### Touch Based Therapies

The power of touch is perhaps underrated in modern society. The simple act of laying a hand on another person's arm or holding someone's hand can be immensely reassuring. Massage, Aromatherapy, Acupuncture and Reflexology are among the most common and widely used touch therapies and the most likely to be of potential benefit to someone with PSP or CBD.

One of the main aims will be to relieve stress and tension in joints and muscles, and to free blocked energy, in order to help the patient feel more comfortable and relaxed.

### Acupuncture

Acupuncture is part of the ancient and complex system of traditional Chinese medicine. Thin, sterile, metallic needles are inserted along specific pathways or meridians to stimulate energy fields in the body and release blocked energy. Acupuncture is well tolerated if performed by an experienced acupuncturist.

For further information contact: The British Acupuncture Council (BAC), 63 Jeddo Road, London W12 9HQ. Tel: 0208 735 0400. Website: [www.acupuncture.org.uk](http://www.acupuncture.org.uk)

The following three therapies are related to Acupuncture but rely on finger pressure instead of needles:

### Acupressure

In Acupressure the theory is the same but hands and fingers apply the pressure instead of needles.

### Shiatsu

Shiatsu is an ancient Japanese form of massage which again has its origins in Chinese medicine and works on the same theory as acupuncture. This massage therapy is generally considered low risk but therapists need to take great care with areas such as the neck

where too much pressure has been known to cause injuries.

For further information contact: The Shiatsu Society (UK), Eastlands Court, St Peters Road, Rugby, Warwickshire CV21 3QP.  
[www.shiatusociety.org](http://www.shiatusociety.org)

## Reflexology

Reflexology is based on the principle that all the organs of the body have corresponding reflex points on the feet. There are also some on the hands. Manipulation and massage of these points can release blockages and toxins and restore a free flow of energy to the whole body. Tender reflex points can indicate an imbalance in a particular organ. The sensitive touch of the reflexologist can detect tiny deposits and imbalances in the body and these points are massaged with the finger tips. The full massage of both feet can take up to one hour and many reflexology clients report feeling relaxed and rejuvenated after this treatment.

For further information contact: The Association of Reflexologists, 27 Old Gloucester Street, London. WC1N 3XX. Tel: 0870 567 3320. Email: [info@aor.org.uk](mailto:info@aor.org.uk)

## Aromatherapy

Aromatherapy was practised in different ways both in ancient China and ancient Greece. The form used today was developed in France in the last century.

It uses essential oils from plants which are applied to the skin, mixed in bath water or inhaled. It should be noted that in a few cases the oils can cause an allergic reaction.

This has been used with patients with neuro-degenerative conditions. Aromatherapy is calming and soothing and may help to diminish anxiety and tremor. Some improved function has been noted in MS patients and other studies suggest improvements in levels of anxiety, pain and insomnia. Many people enjoy the treatment and feel better for it even if they can't confirm or offer proof of lasting results. The Aromatherapy Consortium is made up of different organisations seeking to establish professional standards and a register of qualified practitioners.

For further information contact: The International Federation of Aromatherapists (IFA) 182 Chiswick High Road, London W4 1PP. Tel: 0208 742 2605. Website: [www.ifaroma.org](http://www.ifaroma.org)

## Massage

There are many different types of massage, some using oils and some not. Massage stimulates and energises the body and leads to a feeling of calmness and relaxation. Squeezing, rubbing, kneading and stroking techniques are used to diminish aches and pains caused by muscle and joint stiffness. Indian Head Massage is particularly good for the head neck and shoulders.

For further information contact: The British Massage Therapy Council (BMTc), 17 Rymers Lane, Oxford. OX4 3JU. Website: [www.bmtc.co.uk](http://www.bmtc.co.uk)

## Bowen Technique

This is another non-invasive, holistic therapy. Thumbs and fingers are used to make gentle, rolling type moves to stimulate the muscles and soft tissue. The Bowen technique is said to improve the quality of life for those who are terminally ill as well as relieving many other symptoms.

For further information contact: The Bowen Therapists' European Register (BTER), PO Box 2920, Stratford on Avon, CV37 9ZLS. Tel 07986 008 384. Website: [www.bter.org](http://www.bter.org)

## Cranio-sacral therapy

A gentle but powerful holistic therapy developed from cranial osteopathy which uses touch on the skull and spinal column. Changes caused in the cerebro-spinal fluid are believed to affect the cells of the body via the connective tissue. This therapy therefore claims to help with pain and movement difficulties as well as central nervous system disorders.

It has a relaxing effect on the mind and body and anecdotal evidence suggests that it has benefited Parkinson's patients.

For further information contact: The Cranio-sacral Therapy Association, Monomark House, 27 Old Gloucester Street, London WC1 3XX. Tel 07000 784 735. Website: [www.craniosacral.co.uk](http://www.craniosacral.co.uk)

## Osteopathy & Chiropractic

These techniques involve the manipulation of bones and muscles. They can help with rigidity, stiffness, aches and pains. For further information contact:

- Osteopathy House, 176 Tower Bridge Road, London SE1 3LU. Tel: 020 7357 6655. Website: [www.osteopathy.org.uk](http://www.osteopathy.org.uk)
- General Chiropractic Council, 44 Wicklow Street, London WC1X 9HL. Telephone 020 7713 5155. Website: [www.gcc-uk.org](http://www.gcc-uk.org)

## Reiki

Reiki is a newer form of therapy in the West. It was developed in Japan in the 1800's and the theory is based on practitioners being able to draw on and channel healing energies from the patient's own body. In this respect it resembles healing. It is not recommended for patients with diabetes or Pacemakers.

For further information contact: The UK Reiki Federation, PO Box 1785, Andover. SP11 0WB. Tel: 01264 773774. Email: [enquiry@reikifed.co.uk](mailto:enquiry@reikifed.co.uk)

## Movement Based Therapies

The following are movement activities which are very useful for keeping active. Ideally when they have learned a few gentle moves, patients can practise themselves or do them with a carer on a daily basis. This can help circulation and digestion and can help to conquer aches and pains from being inactive or having limited mobility. Of course, they're only useful as long as the patient is able or motivated enough to do them.

## Alexander Technique

This is particularly useful for any patients with back and neck problems. The aim is to help improve posture and movement and thereby eliminate pain and stress in the joints. It is also believed to help with breathing and depression.

The technique was developed by an Australian actor, Frederick Alexander, in about 1900 after he overcame his vocal problems by finding ways to release tension in the neck and back. It involves learning techniques to move and support the body in a more economical and relaxed way.

Dr Chloe Stallibrass carried out a trial (sponsored by The PSP Association) on a PSP patient in 2000. This involved an intensive course of 40 lessons. Both the patient and Dr Stallibrass felt they had benefited considerably!

Alexander Technique teachers do not have to belong to any organisation or have a qualification, however all members of The Society of Teachers of the Alexander Technique have completed a training course and agree to a professional code of conduct. The society will give details of its members.

For further information contact: The Society of Teachers of the Alexander Technique (STAT), 1st Floor, Linton House, 39-51 Highgate Road, London NW5 1RS. Tel: 0207284 3338. Website: [www.stat.org.uk](http://www.stat.org.uk)

## Tai Chi

Tai Chi can be useful for people with PSP if there is a suitable teacher willing to work with them. This also depends on the patient's degree of mobility and willingness to engage in this form of exercise.

Tai Chi can help with muscle stiffness, improve balance and relax the mind. It is based on Chinese martial arts practices but is also a gentle exercise routine and a form of moving meditation. All the moves are calm and slow and aim to relax and unblock the energies of the body and mind.

For further information contact: Tai Chi Union for Great Britain, 1 Littlemill Drive, Balmoral Gardens, Crookston, Glasgow G53 7GF. Tel: 0141 810 3482.

## Yoga

Many yoga teachers now use a series of gentle moves which can be done with limited movement or in a sitting position. These are generally used for older people or patients with movement difficulties.

For further information contact: British Council for Yoga Therapy Website: [www.bcyt.co.uk](http://www.bcyt.co.uk)

## Other Therapies

### Relaxation & Meditation

The aim of meditation is to create a sense of calm in the mind. Through gentle and regular breathing a state of restful alertness may be achieved which can help someone to cope with stress, find solutions to problems and relax the body. There are many centres throughout the UK offering meditation. For further information contact The Transcendental Meditation Association. Tel: 08705 143733. Website: [www.t-m.org.uk](http://www.t-m.org.uk)

### Healing and Faith

Care should be taken when approaching a healer, particularly if expansive claims are made or the cost is high. There is no way of assessing healing and one can only go on the claims made by those who have experienced it. In some cases the laying on of hands can appear to have a powerful restorative effect which seems both calming and energising but this may not last or show any obvious physical benefits.

Most healers believe they are channelling the natural energy around us to repair individual energy fields. The strengthening of a person's particular faith can also help both patients and carers in living with a progressive illness.

For further information contact: The Confederation of Healing Organisations (CHO), 250 Chichester Road, Portsmouth, Hampshire PO2 0AU. Tel: 023 9271 3607. Website: [www.confederation-of-healing-organisations.org](http://www.confederation-of-healing-organisations.org)

### Herbal Medicine

Herbs contain numerous chemical constituents and some can react with conventional medicines or provoke symptoms. In fact many modern drugs are related to chemicals found in herbs. There are four basic types of herbal medicine: Chinese, Ayurvedic (Indian), Tibetan and Western. For further information contact: National Institute of Medical Herbalists, 56 Longbrook Street, Exeter EX4 6AH. Tel 01392 4206022. Website: [www.nimh.org.uk](http://www.nimh.org.uk)

## Homeopathy

The principles of Homeopathy appear to be contrary to conventional medicine and based on the idea that extremely dilute preparations can offset large amounts of the same substance to relieve the symptoms caused. There is concern that responses to herbal preparations may be 'placebo responses'. However, because the preparations are very dilute, homeopathy is thought to be relatively safe.

For further information contact: The British Homeopathic Association, Hahneman House, 29 Park Street West, Luton LU1 3BE. Tel: 0870 444 3950. Website: [www.trusthomeopathy.org](http://www.trusthomeopathy.org)

## Hydrotherapy

This involves water exercises and may be appropriate for patients who have previously enjoyed swimming and being in water. It eliminates the risk of injuries by falling and prevents the body overheating during exercise. There is some evidence that this has helped MS patients with walking and it can improve muscle stiffness.

For further information please contact: The Chartered Society of Physiotherapists, 14 Bedford Row, London WC1R 4ED. Tel 020 7306 6666. Website: [www.csp.org.uk](http://www.csp.org.uk)



# Holidays



So why take a holiday? Perhaps you thought that a PSP diagnosis meant that holidays were a thing of the past. Holidays can provide a vital break both for people with PSP and their carers.



Obviously you need to be realistic about the level of disability and any extra requirements when planning a holiday. But the good news is that there's plenty of help and advice available.

Accessibility, insurance, medical facilities and possible extra costs are likely to be additional factors you need to think about when booking a holiday involving someone with PSP.



The aim of this section is to provide signposts to some of the help that's available. Please note that The PSP Association does not specifically recommend or endorse any of the companies or products mentioned in this leaflet.

It's a good idea to consult your doctor about your trip. Ensure you have all the prescriptions you need plus any non-prescription medication. Before you leave, check out access to toilets en route, particularly on planes if flying long distance.

You will also need to have hospital details and contacts for emergency medical assistance at the destination and should check whether your dietary needs can be met.

It is wise to contact the company 48 hours before departure to check that your arrangements are recorded and in place. It may also be a good idea to pack your Carer's Information Pack – if you have room in your suitcase!

Above all, having made all these preparations – have a very good holiday!

## Trains, Boats and Planes

### Trains

#### UK

The Department for Transport has introduced a scheme called 'Access for All'. All new trains, by law, now have to be accessible to disabled people and railways stations are becoming more accessible.

You may be eligible for a disabled person's railcard, entitling you to 1/3 off rail fares. If you do not have a railcard but need to remain in your wheelchair for the duration of the journey, you will be eligible for a discount. For more information on the above, and to find out about accessibility of stations on your journey, telephone National Rail Enquiries on 08457 48 49 50.

#### Eurostar

Eurostar have a specially adapted area of the train to accommodate wheelchair users. Special fares apply and the person accompanying you will be eligible for a reduced fare. Eurostar do not provide wheelchairs so you must bring your own. Enquiries telephone number 08705 186 186.

#### Eurotunnel

The Eurotunnel is a good way to reach the continent from the UK if you want to drive your own car. You can stay in the car for the journey if you wish, and the terminal buildings have good access facilities.

### Ferries

#### Access and Assistance

If driving, then getting on to the boat won't be a problem but getting from the car to the passenger deck may be awkward. Always check with the ferry company. At the time of booking, tell them about the help you might need. Many ferries have lifts between decks, but make sure your car is loaded close enough to the lift to be able to use them!

#### Some Good Deals

Some ferry companies offer special deals for disabled passengers. Check with the company, to get the best deal. Disable Motoring UK

[www.disabledmotoring.org](http://www.disabledmotoring.org) or call 01508 489 449) promote mobility for disabled people and issue a booklet on ferry concessions. Members of Mobilise are also entitled to discounts on journeys with many ferry operators.

## Cruises

A cruise is a good way of taking a break if there are difficulties moving about. Care services are near at hand and you can enjoy the open air, good food and meeting other people.

There's a constantly changing scene before your eyes with interesting ports, landscapes and harbours to enjoy even if you can't leave the ship. Many excursions can cater for wheelchair users. Some cruise lines specialise in cruises for the disabled and can arrange for a nurse to accompany you on the holiday. In some cases, it may be necessary to fly to the start of a cruise but there are also plenty leaving from the UK.

### Access and Assistance

Cruise ships offering services for the disabled have spacious and accessible cabins, wheelchair-friendly areas, lifts and up to date medical services. Again, always check in detail that the particular ship or cruise can fulfil your medical requirements. When booking ask if the cruise line has a special needs brochure detailing the amenities offered to those with disabilities.

### Advice

The CruiseCritic website gives advice on cruising and details of ships for those with disabilities. ([www.CruiseCritic.co.uk](http://www.CruiseCritic.co.uk) then click 'cruise style' and then 'Disability')

### Some Good Deals.

- Cruisingholiday.co.uk is a commercial cruise line specialising in cruises for the disabled. See [www.Cruisingholiday.co.uk](http://www.Cruisingholiday.co.uk) or call 0844 800 2624 for further information.
- Seagull Trust Cruises offer free day cruises on Scottish lowland canals on the *Marion Seagull* (sleeps 6) or longer cruises (not free) for a group or family with one disabled member. See [www.seagulltrust.org.uk](http://www.seagulltrust.org.uk) but write to Canal Side, Baird Road, Ratho EH28 8RA for bookings or email [seagulltrust@btinternet.com](mailto:seagulltrust@btinternet.com).

## Air Travel

Since July 2008, new European regulation means that airports will have to provide services that enable disabled passengers to board, disembark and transit between flights.

The Equality and Human Rights commission have produced a booklet called 'Your Right to Fly', which sets out what this new law means for you, and helps you plan your journey by air. You can download a copy at [www.equalityhumanrights.com](http://www.equalityhumanrights.com), or telephone 0845 604 6610.

### Some other considerations:

- Some carriers require a MEDIF (standard medical form) to be completed by the traveller's doctor.
- If an oxygen supply is required during the flight, this must be arranged with the airline. You cannot take your own supply but may be required to bring your own mask.
- If you're taking your own wheelchair you need to consult with the airline first and ensure that any necessary maintenance is carried out beforehand and that you have spare parts. Airlines will not take chairs with lead-acid batteries unless they have been specifically cleared for airfreight. Gel or foam-filled batteries are the best solution.
- You will also need a transformer for recharging if the voltage at your destination differs (e.g. for USA) from the UK.

### Advice

- The website [www.flying-with-disability.org](http://www.flying-with-disability.org) provides comprehensive advice on flying with a disability and the Spinal Injury Network website, [www.spinal-injury.net](http://www.spinal-injury.net) provides useful tips on flying with a disability.

## Insurance

Premiums may be higher for people with PSP, but it is not generally difficult to obtain insurance. Some insurance companies that we are aware of are:

- [www.freedominsure.co.uk](http://www.freedominsure.co.uk) will insure those with neurological conditions to travel by plane.

- AllClearPlus: Provides a special policy for travellers with pre-existing medical conditions/disabilities.  
Regent House, Hubert Road, Burntwood, Essex CM14 4JE.  
Website: [www.allcleartravel.co.uk](http://www.allcleartravel.co.uk) or call 0845 250 5200
- Free Spirit: For travellers with medical conditions or disabilities.  
Milton Barr House, Bridge Mews, Bridge Street, Godalming, Surrey GU7 1AZ. Website: [www.free-spirit.com](http://www.free-spirit.com) or call 0845 230 5000
- Age UK (England)  
Free quote on [www.ageuk.org.uk](http://www.ageuk.org.uk) or call 0845 600 3348
- Saga Special Holidays  
Saga Building, Enbrook Park, Sandgate, Kent CT20 3ZH. Website: [www.saga.co.uk/finance/travelinsurance/](http://www.saga.co.uk/finance/travelinsurance/) or 0800 015 8055
- JD Consultants. Covers all conditions and destinations excepting a terminal prognosis of less than 4 months:  
44 High Street, Orpington, Kent BR6 7BA 020 8464 6636 [www.jdtravelinsurance.co.uk](http://www.jdtravelinsurance.co.uk)
- Chartwell Insurance Specialists in disability and travel  
292-294 Hale Lane, Edgware, Middlesex, HA8 8NP Website: [www.chartwellinsurance.co.uk](http://www.chartwellinsurance.co.uk) or call 0800 089 0146.

## Funding Assistance

Many charities will offer financial support for holidays (see the Charitable Support in the Work, Benefits and Finance section.) In addition, the Disability Aid Trust give grants towards the cost of helpers to assist disabled people on holiday and to give carers a break. Tel: 0800 028 0647  
[www.disabilityaidtrust.org.uk](http://www.disabilityaidtrust.org.uk)

## Saga Respite for Carers Trust

The Saga Respite for Carers Trust will cover the cost of much-needed holidays for carers and their companions, and will ensure continuity of care. Hundreds of holidays are offered including river and ocean cruises, UK and European breaks and locations further afield. SAGA

will also provide spending money and travel insurance if required.

The carer should:

- be over 50
- have been caring for someone for over a year
- not had a significant holiday away from their caring role in the last year
- and not be a professional carer.

You can nominate yourself or be nominated. Download a form from the 'Care' section at [www.saga.co.uk](http://www.saga.co.uk) or send a self addressed envelope to: The Trust Manager, Saga Respite for Carers Trust, The Saga Building, Enbrook Park, Folkestone, Kent CT20 3SE.

## General Help and Advice

In addition to our Getting About section, the following information is tailored towards holidays for the disabled:

- **Rough Guide to Accessible Britain**

Full of ideas for accessible days out across the UK. This book is free for all blue badge holders (except for postage and packing at £1.99) or £6.99 for all others. Tel: 0800 953 7070.

- **Tourism For All**

Provides access advice: [www.tourismforall.org.uk](http://www.tourismforall.org.uk) or call 0845 124 9974 (for access advice) or 0845 124 9971 (other information.)

- **RADAR (Royal Association for Disability and Rehabilitation)**

Visit [www.radar.org.uk](http://www.radar.org.uk) and enter 'Holidays' in the Search box or call 020 7250 3222, for information and guides to holidays and travel.

## Door to Door

The website of the Disabled Persons Transport Advisory Committee (DPTAC). It provides advice to disabled people about travel using all forms of transport. <http://dptac.independent.gov.uk>

# Later in Life





# Continuing Care

PSP is a progressive disease and there may come a time when you need paid help. This can consist of:

- **Social Care**

This is sometimes called personal care and is provided by the local authority. Payment is means-tested.

- **Health Care**

This is sometimes called nursing care and is provided by the NHS. Health care is free to the user and includes nursing care and the assistance of appropriate therapists.

The dividing line between health and social care is sometimes obscure and sometimes influenced by local funding issues. Joint funding arrangements are being introduced in some areas, making the process simpler.

When the patient is assessed as having a need for Social Care, but their **primary** need is for Health Care, the full care and funding responsibility passes to the NHS and is generally known as **Continuing Healthcare** (abbreviated to Continuing Care). This is unlikely to be needed when first diagnosed, but it is important that you are placed in the system to ensure that you are routinely reviewed.

## Getting Help

The two important entry points to getting help are:

- The Needs Assessment
- A Screening for Continuing Care

If you are dealing with a health or welfare professional who you think doesn't understand PSP, put them in contact with your PSP Nurse Specialist.

## The Needs Assessment

People with PSP are legally entitled to a Needs Assessment. Your GP will give you the appropriate contact and it will be a joint assessment between the NHS and the Local Authority. Carers can ask for their own separate assessment – see our section Support for Carers.

You should **ask for an Assessment** even if you have private medical insurance or suspect that you won't be entitled to any financial help. This is because it provides a professional assessment of your needs, and the NHS and Local Authority will be aware of them, making it much easier to get help.

The Assessment provides a written summary of:

- the care needs of the person with PSP.
- The help and equipment required to meet those needs, and how best to provide it, be it Social Services, the NHS or an independent provider. Advice may be offered about other organisations that may also help.
- When the next review is due. You should ask for this to be brought forward if you think your situation is changing.

As appropriate, the Assessment should include:

- Health Services including Speech and Language Therapy, Physiotherapy, Dietician and Nursing Care.
- Occupational therapy, including equipment and adaptations to the home.
- Access to Day centres and Luncheon clubs.
- Care at Home, including whether this should be by providing carers or providing direct payments to you to fund and organise carers.
- Care home placements.

## Social Care Provision

If the Local Authority funds an element of the Social Care Need, it may provide the help directly, or it may give you a sum of money to purchase that care yourself under systems such as Individual Budgets or Direct Payments.

These give you flexibility to decide, within certain limits, what care you need and when. About 15% of Local Authorities had moved to Direct Payment by end-2010, but the Government is pressing for universal adoption.

## Registering for Continuing Care

The process consists of:

- Initial Screening
- A Full Consideration
- Regular Reviews
- An Appeals Process

## Initial Screening

Request a Screening for Continuing Care as soon as significant problems with day-to-day living arise for the person with PSP. Your GP, Social Worker or Nursing Home Matron can carry out the Screening.

If the outcome of the screening is that a Full Consideration isn't recommended, then a date should be set for the next review (see Reviews below).

You may also be eligible for a weekly payment if you live in a care home that is registered to provide nursing care and you need the services of a registered nurse.

If the Screening recommends a Full Consideration, then it will be passed to the NHS for a decision.

## Full Consideration

If the Screening process indicates that Continuing Care may be justified **and** the NHS Primary Care Trust agrees, they should nominate a single point of contact for a more detailed assessment, known as a Full Consideration.

You may wish to discuss your case with the PSP Nurse Specialist before being assessed.

The time between a referral for an assessment and a decision shouldn't normally be more than two weeks. **The Assessment should take into account how things are on a bad day, not on a day when things are going well.**

The Full Consideration will be carried out using the 'Decision Support Tool' that will record the level of need in 12 'care domains' to build a picture of complexity, intensity and unpredictability.

Each domain is assessed on a scale, from No need, through Low, Moderate, High and some, as indicated, have higher scores of Severe, and then Priority. The 12 care domains are:

1. Behaviour - up to Priority
2. Cognition - up to Severe
3. Communication
4. Psychological or Emotional Needs
5. Mobility - up to Severe
6. Nutrition - up to Severe
7. Continence
8. Skin (including tissue viability) - up to Severe
9. Breathing - up to Priority
10. Symptom Control (Drug Therapy and Medication) - up to Priority
11. Altered state of consciousness - up to Priority
12. Other Significant Care Needs - up to Severe

Note that sight is not directly assessed, although it could have an indirect affect on several areas above, and Domain 12 above is very much up to the assessor.

The guidelines for authorising Continuing Care are:

- One or more domain is assessed as Priority *or*
- Two or more domains are assessed as Severe *or*
- There is one Severe need and a number of other domains are assessed as Moderate or High, *and* the assessment team considers that Continuing Care is justified.

Some examples of where people with PSP or CBD have made a successful application for Continuing Care are when the applicant was:

- Immobile and incontinent, and had difficulty communicating *or*
- Risked choking or aspirating (taking food or drink into the lungs) to the point that feeding needed constant supervision *or*
- Had behavioural disturbances to the extent that supervision by a psychiatric nurse was needed

## The Decision

The Full Consideration will be decided by a separate panel who may decide:

- Continuing Care is not required now, but a **review** must be carried out no later than annually, and earlier if the condition is deteriorating rapidly.
- Continuing Care is not required now, but some care by a Registered Nurse is needed. In this event, the decision should be **reviewed** within three months. If the applicant is in a Care Home, then a flat weekly payment may be made towards the cost of nursing.
- Continuing Care is required immediately

## Reviews

An important element is the Review. This should be done:

- At least annually after initial screening if nursing care isn't provided. For PSP and CBD, press for the reviews to be more frequent.
- At no more than three-month intervals if you are receiving nursing care.

The screening and reviews ensure that you are 'in the system.' If your situation changes between reviews, request that the next one is brought forward.

## Appeal

An Appeal process will be explained to you if Continuing Care isn't granted. 56% of appeals heard in 2007/8 were successful, so it is often worth appealing. Your PSP Nurse Specialist will be pleased to advise.

## About Continuing Care

For PSP patients, Continuing Care may include:

- Palliative care
- Respite health care
- Specialist health care support, equipment and transport.

In many cases, Continuing Care is provided in a residential home with accommodation, personal care and nursing care being the responsibility of the NHS. However, Continuing Care may be partly or fully provided:

- At home
- In a care home without nursing care (a residential home)
- In a care home registered to provide nursing care (a nursing home)
- In a hospital or a day hospital
- In a day centre
- In a hospice

Family wishes will be considered, but the final decision rests with the NHS.

## Transfer from Local Authority to NHS

A possible problem that can arise when moving on to Continuing Care is when the Local Authority have been making Direct Payments for their element of the care package, giving the direct carer flexibility.

When Continuing Care is awarded, the NHS may not provide such a flexible system.

*This information applies to England. Similar systems operate in the rest of the UK although other countries may provide more financial support where means testing is indicated.*



# Choosing Care



## Care at home or in a Home?

There may come a time when the person with PSP and their family decide that a move from the family home into residential care would be best for everyone concerned.

Some do this but others decide to stay in the family home. There is no universal answer and every family will reach their own decision in good time.

Many factors influence this decision, taking into account the ability of the family and the health and welfare services to provide proper support at home.

If the family wants the person with PSP to stay at home, it certainly should be easier than a few years ago. This is because the Government now promotes care at home when it is the person's preferred choice.

The Local Authority is not permitted to set a limit on the care it will fund at home or in a home or to force someone into residential care against their will, although financial assistance will be means-tested and may be limited.



## Standards

The Care Quality Commission carries out inspections of care services and all registered care homes, many carried out at no notice. Reports are available at <http://www.cqc.org.uk/findcareservices.cfm> or call 03000 616 161.

## Options

### Residential and Nursing Homes

A Nursing Home is a Residential Home that also has qualified nursing staff on a 24-hour basis. Most of the staff will be unqualified, although trained in the task that they cover. A Nursing Home is more likely to be suitable for people with PSP although some people have received

satisfactory care in a Residential Home with visiting nursing support. Many Homes offer day care, which can be increased to residential if needed.

## Hospice

An increasing number of hospices now offer services for people with neurological conditions such as PSP. These may include outreach teams to help to support you at home, and beds in the hospice at an appropriate point.

As yet, there is no overall register of which hospices offer services for neurological patients in the UK, so you will need to find out locally.

Approach the hospice direct or obtain a referral from your GP. You can find where your nearest hospices are by contacting Help the Hospices at:

[www.helpthehospices.org.uk](http://www.helpthehospices.org.uk) and click on Find a Hospice, or call 0207 520 8222 (Mon-Fri 0800-1700).

If you live outside the UK, the same Help the Hospices website and helpline offers excellent information about hospices and support organisations in your country.

## Choosing A Care Home

Selecting a Care Home may be a difficult decision. Cost may be an important factor, but choosing a home that provides the right degree of care and support will be your first priority. There is a vast amount of information available and this section only aims to give a few pointers to assist you in the task.

## Knowing What's Available

Many organisations offer help and advice in selecting a Care Home. Social Services and your local Branch of Age UK will provide lists of Homes in your area. The Elderly Accommodation Counsel will also provide you with detailed information on the Homes in your area ([www.housingcare.org](http://www.housingcare.org)) or the Advice Line on 0800 377 7070.

## Personal Recommendation

The most important element of any care home is the motivation, training and commitment of the staff. A personal recommendation may be an important factor in choosing a home, especially from another subscriber to the PSP Association that you may have met at a Support Group or other contact.

## Inspection

Visit a number of homes, even if you already have one in mind. This will give you some comparisons. Before you visit:

- Compile a list of questions. AGE Concern publishes a Care Home Checklist - see [www.ageuk.org.uk](http://www.ageuk.org.uk) or call 0800 00 99 66.
- Complete the 'Into Hospital' section included in this Guide, so that you can discuss the specific issues surrounding PSP with the Home, to understand how they would provide the support needed.
- Check whether your PSP Nurse Specialist is available to give a training session for the Home staff. (This will depend on the size of the likely audience, travel costs and time.) Check whether the Home would welcome such a visit and be prepared to pay some or all of the costs involved – this might provide an indication of their commitment.

## Funding

Some people with PSP who enter residential care will be entitled to Continuing Care (see section Getting Help) and the NHS should fund the care home fees.

If Continuing Care is not authorised, funding responsibility for care home fees varies across the UK and Ireland and we recommend that you seek local advice from organisations such as the Citizens' Advice Bureau or Age UK. A comprehensive guide is also available from the Disability Alliance, [www.disabilityalliance.org](http://www.disabilityalliance.org) or call 0207 247 8776. In essence, there are two options:

- You can fund the place yourself
- The Local Authority (LA) will fund the placement up to the cost that it would incur if it contracted directly with a home in the area if:

- You pass a means test that takes into account your assets and income *and/or*
- You're unable to make your own arrangements or others are unable to make the arrangements for you

You will be liable for any difference (known as 'top-up fees') between the cost of the Home to you and what the Local Authority assesses it would pay if it contracted directly, for example with another Home.

In both instances, any care assessed as Nursing Care should receive a contribution from the NHS, and this will be assessed when you enter the Home.



# Brain Donation



Brain donation is an important way to help research into the treatment and eventual cure of PSP and CBD. It offers a lasting legacy to help others in the future. However, it's important to plan ahead, to ensure your wishes are met.



## Here are a few pointers to help.

Members have overwhelmingly told us that research really matters to them. In our member survey in 2010 they told us that they think that the PSP Association should be at the forefront of spearheading research into treatments and a cure.



We fund the Sara Koe PSP Research Centre (SKRC) which is co-located with the Queen Square Brain Bank for Neurological Disorders at the Institute of Neurology in London. The team has over 10 years' experience and are available to discuss the importance of brain donation with patients, relatives and the public, so that consent can be given in an informed way.

Research using human brain tissue has increased the understanding of many brain disorders such as Parkinson's and Alzheimer's disease. However, conditions such as PSP or CBD remain relatively poorly understood and require further investigation.

Brain donation is an important tool in the research armoury. It can also help to salvage meaning from an otherwise distressing situation, by contributing towards advancing medical knowledge, helping others in the future, and giving a final confirmation of diagnosis. There is no clear diagnostic test as yet for people living with PSP or CBD.

## Register early

Brain tissue needs to be donated soon after death to be useful for research. There is also some important paperwork to complete, to ensure your wishes are met and to enable everything to proceed smoothly when the time comes.

Sadly, we still receive calls from people who's loved one has died and wanted to be part of the scheme but never registered, or who call too late for donation to take place. Planning ahead helps to reduce stress – and in some cases, distress.

## Let your family know

When you die, your body becomes the ‘property’ of your next of kin, in the following order – your spouse, adult children, parents, siblings. Whoever has responsibility will have the final say in the matter.

If you want to be a brain donor, make sure your family knows your wishes. Every family is different, but it helps to plan ahead and talk as openly as you can. It may help to ask someone to support you in this – it could be a key worker or friend.

## Keep details to hand

To help everything run smoothly and save you added stress at a difficult time, keep any paperwork – particularly the brain bank number, 020 7679 4266 – to hand, so you can get in touch with them quickly.

## Donation needs to take place within 48 hours

The brain can’t be kept alive with machines the way the heart can, so donation needs to take place within 48 hours after death. And brain tissue isn’t used for a transplant like the heart or kidney—its tissue is for research only. It helps if decisions are already made and registration completed in advance.

## Reassurance

Families are sometimes concerned by the ‘thought’ of brain donation, but everything is done carefully and sensitively. An incision is made at the back of the head at the hairline, the person is not disfigured in any way and you can’t tell that the brain has been removed.

## Healthy brains are important too

Researchers need brain tissue from both healthy people and those with neurological disorders, so family or friends without neurological conditions are welcome to register as donors. Healthy tissue helps to provide researchers an understanding of the normal function of the brain, in order to compare.

If you wish to discuss brain donation please contact Susan Stoneham, SKRC Administrator, on the SKRC line: **020 7679 4266**, or alternatively, 020 7837 8370.



# Legal Issues



## Introduction

As many people with PSP will find it increasingly difficult to communicate their views on how they want to be treated and supported as the disease progresses, it's a good idea to discuss things in advance. This way you can help them formally record their decisions to ensure that their wishes are carried out as far as possible.

This section aims to provide pointers on how to go about this. It covers the situation after the Mental Capacity Act 2005 (The Act) came into force during 2007 and applies to England and Wales. Scotland has separate legislation under the Adults with Incapacity (Scotland) Act 2001.

This is only an introduction to the topic - do seek legal advice before taking action and read the more detailed information available from the Ministry of Justice (see Contacts below).



## General Provisions of the Act

The Act protects people who lose the mental capacity (see below) to make or to communicate their own decisions (in this case through PSP) by:

- Enabling them to state their wishes in advance to **refuse** specific medical treatments or procedures. This is called an **Advance Directive to Refuse Treatment (ADRT)** and can be legally binding. For example, a decision not to insert a PEG if swallowing becomes difficult might be covered by an ADRT.
- Permitting them to indicate in advance what medical treatment they **would** wish to receive. Such statements must be taken into account when decisions need to be made, but are not binding on carers and health professionals in the same way as an ADRT.
- Enabling them to appoint someone in advance to make their health, welfare and/or financial decisions. That person ('the Attorney') would be appointed by the person with PSP ('the donor') by a formal document called a **Lasting Power of Attorney (LPA)**. There are two different types of LPA:

- **A Personal Welfare LPA** for decisions including where to live, day-to-day care and medical treatment. It can **only** be used when the donor is unable to make a particular health or welfare decision themselves.
- **A Property and Affairs LPA** for decisions including finance and selling the donor's house. If the donor so specifies, this LPA can be used at any time after it is registered.

The person ('donor') may appoint different attorneys for each LPA if they wish and can limit what decisions they may or may not make. The attorney has a legal duty **to act in the best interests of the donor** after considering their preferences and involving the donor as far as possible in the decision. An attorney is generally unable to overrule an ADRT.

To appoint an attorney, you should seek legal advice or obtain a special form from the Office of the Public Guardian (see Contacts below). Some legal bookshops can also supply the documents.

- Appointing someone ('the Deputy') to act in the person's best interests if the person lacks mental capacity and has not appointed an Attorney. The Deputy will be appointed by the Court of Protection, who will limit the scope of the powers granted to the minimum that is needed. A carer can apply to be appointed as a Deputy, and application forms are available from the Office of the Public Guardian (see Contacts below.)

The Act also defines procedures to ensure that the person's rights are protected, defines the responsibilities of health professionals involved in making medical decisions and defines an appeals process.

## Mental Capacity

A person is judged to lack mental capacity if they cannot:

- Understand the information given to them *or*
- Retain that information long enough to make a decision *or*
- Weigh up the information available to make a decision *or*
- Communicate that decision by any means.

Although simply stated, the interpretation can be complex both for you and any health professionals involved and you should take further advice

if in doubt. It is most important to note that the Act states that everyone should be treated as able to make their own decisions unless it is shown that they cannot. If they are able to make their own decision at the time it is needed, then that decision overrides any ADRT or those of anyone granted Power of Attorney.

## Agreements Drawn up before the 2005 Mental Capacity Act Came Into Force

The 2005 Act significantly changed the legal framework around such issues as Power of Attorney and Advanced Directives ('Living Wills'). Such agreements drawn up before the Act came into force will probably retain their legal status but you should take action to confirm this.

- Enduring Power of Attorney (EPA). If an EPA has been activated, then the person appointed as attorney carries on as before for financial decisions, acting in the best interest of the donor. If an EPA has been registered but not activated, then it may be kept for financial decisions. Alternatively, a new document (Lasting Power of Attorney for finance and property) could be drawn up. In any event, a new Lasting Power of Attorney for welfare decisions will be needed if the donor requires it.
- Advance Decision (or 'Living Will'). If the person that you care for already has an Advanced Decision, then it may still be valid. However, you should take advice or check it against the guidance at [www.dh.gov.uk/consent](http://www.dh.gov.uk/consent)

### Contacts:

Information and Application Packs for Lasting Power of Attorney, Advanced Directives or the appointment of Guardians may be downloaded from:

England and Wales: [www.publicguardian.gov.uk/](http://www.publicguardian.gov.uk/) or 0207 664 7000.

Scotland: [www.publicguardian-scotland.gov.uk](http://www.publicguardian-scotland.gov.uk) or 01324 678300

Copies of the Mental Capacity Act 2005 and the Code of Practice may be obtained from:

[www.dca.gov.uk/legal-policy/mental-capacity/index.htm](http://www.dca.gov.uk/legal-policy/mental-capacity/index.htm) or 0870 600 5522

## Wills

Everyone should make a will. If they don't, their estate will be divided up on their death under the legal rules of Intestacy, following a somewhat arbitrary formula that probably won't reflect the individual's wishes.

### Why is it important to make a will?

Only the individual knows what they would like to happen to their estate. Someone with the correct qualifications will be able to make sure that there is no opportunity for misinterpretation of their wishes.

A will is one of the most important documents people ever sign. Telling someone what they want to happen isn't enough and it should never be assumed that a spouse or partner will automatically inherit everything if you don't leave a will.

### As carer, can I help the person with PSP make a will?

An unclear will can result in wrangles and legal costs that will eventually eat in to the value of the estate, causing unnecessary additional heartache to those left behind. We strongly recommend that you seek the help of someone who is properly qualified, such as a solicitor.

A simple will should cost in the region of £150 when drafted by a solicitor.

If you need help to find a local solicitor, The Law Society will be able to assist [http://www.lawsociety.org.uk/choosingandusing/findasolicitor\\_law](http://www.lawsociety.org.uk/choosingandusing/findasolicitor_law) or telephone 020 7242 1222.

Don't forget from time to time circumstances change so it is essential to review your will to ensure it is still relevant. For example you may wish to update it, if you marry, divorce or if children or grandchildren are born.

## Keep the will safe

A lost will is no use to anyone, so make sure that your executors know where it's kept. You can leave your will with a solicitor or bank for safe keeping, or for a small one-off fee of around £15.00, you can deposit it with:

The Safe Custody Clerk  
Probate Department  
High Court of Justice  
First Avenue House  
42 – 49 High Holborn  
London. WC1V 6NP

Telephone 020 7947 6000 to request an information pack and the special envelope in which to place your will.

## Leaving a Legacy to The PSP Association

### How a legacy to The PSP Association will make a difference

Whatever the value of a legacy it will help The PSP Association to support people living with this devastating disease and to provide a secure financial base to further the Association's work to find a disease-modifying treatment and an eventual cure. We need additional funding to:

- Recruit more PSP Nurse Specialists.
- Expand the network of Local Support Groups and make them accessible to many more families.
- Increase our efforts to raise awareness of PSP among health and social care professionals.
- Invest in research to find the causes, treatments and a cure – and strengthen our fight for a world free of PSP and CBD.

If you'd like to discuss any aspect of leaving a legacy to The PSP Association or would like further information please call Lis Nunn on 01327 322419 or email your questions and enquiries to [lis.nunn@pspeur.org](mailto:lis.nunn@pspeur.org)

If you have already remembered The PSP Association in your will and would like to let us know, Lis would love to hear from you.

## How do I go about it?

If you would like to leave a legacy to The PSP Association, or indeed to anyone else, this can be done easily through adding a 'codicil' to your new or existing will. Your solicitor will help you write it. Leaving a legacy to The PSP Association in your will is straightforward, and **is exempt from inheritance tax**.

There are different types of legacy, but the most popular ones are:

- **Residuary Legacy:** Usually shown as a percentage of what is left over after all of your other wishes have been carried out and debts cleared. This type of legacy rises with inflation and is the best way to leave a gift for a charity.
- **Pecuniary legacy:** A specified amount of money.
- **Specific legacy:** A gift that can be in almost any form e.g. house, land, jewellery, paintings, car etc.
- **Reversionary legacy:** a gift of property subject to a prior interest. For example, a house that is left to someone to enjoy in their lifetime but when they die it is passed on to The PSP Association.
- **Contingent gift:** a gift that has certain conditions attached. The PSP Association will be happy to receive a legacy without conditions attached so that it can use the legacy in the best way that it thinks fit. However, you may wish to make a Contingent Gift if, for example, you want the legacy to be used only for research into finding a treatment for PSP, or for greater care and support through the provision of more nurses.



# PEG Feeding



Sometimes in PSP & CBD, the person's ability to swallow can deteriorate to a point that makes it difficult to eat and drink enough. This can result in weight loss and increased risk of chest infections or aspirational pneumonia. A PEG (percutaneous endoscopic gastrostomy) is a feeding tube which passes through the abdominal wall into the stomach, so that nutrition can be provided without swallowing, or in some cases used to supplement ordinary food.



Where possible, the decision to have a PEG should be part of a wider discussion on managing symptoms.



This will be between the person with PSP, their care team and you, as carer. It is likely to be part of their specific advanced care plan. This will probably include information on when, and if, the PEG tube would be discontinued.

## When considering the option of PEG feeding, remember:-

- The wishes of the person with PSP are paramount and must be respected. If required, additional guidance is available in the section Later in Life – Legal Issues.
- Discuss the option well in advance of the onset of any serious communication difficulties, preferably with family members and the Speech and Language Therapist.
- A PEG is probably of greatest benefit to those who opt to have the procedure before the need has become a medical necessity

## Possible Advantages

- Food and fluid intake no longer becomes a struggle
- Less risk of food going down the wrong way (aspiration)
- Helps prevent further weight loss
- Medications can be given via the PEG tube
- Food and drink can still be taken by mouth if the person with PSP can safely manage it.

## Possible Disadvantages

- PEG placement is an invasive procedure.
- It is mildly traumatic, requiring a couple of days in hospital.
- The carer will need to be willing and able to learn to use the equipment.
- There is the risk of infection at the entry site.
- Choking on saliva can still occur.

As with so many aspects of PSP, personal experience varies enormously. Some people find that having a PEG improves their quality of life. Others, especially if they have other serious symptoms at an advanced stage, decide that the potential benefits aren't worth having. Experts will advise, but ultimately, only the person with PSP can decide what's right for them.

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