

# Section 1

## Introduction to PSP and CBD

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# Introduction to PSP and CBD



## Introduction

This section gives an overview of PSP and CBD from diagnosis through to symptoms. Remember, not all of this is relevant to everyone, because everyone's journey with PSP is different.



# What is PSP and CBD?



Progressive Supranuclear Palsy and Cortico Basal Degeneration are closely related neurodegenerative conditions. Both are caused by the progressive death of nerve cells in the brain.

## Progressive Supranuclear Palsy (PSP)

The condition gets its name because:

- It gets steadily worse over time – **progressive**
- It damages the nuclei that control eye movements – **supranuclear**
- It causes weakness – **palsy**.

## Cortico Basal Degeneration (CBD)

Is so called because:

- It affects the brain cortex – **cortico**
- It also effects other areas of the brain, including the basal ganglia – **basal**
- It destroys nerve cells in the brain, causing **degeneration**.

PSP is associated with the over production of a protein called 'tau' in certain areas of the brain. Researchers are still unsure as to the precise cause of PSP but it is thought to result from a combination of genetic and environmental factors.

PSP is a rare condition and research into the prevalence of the condition suggests that there are around 4,000 people in the UK living with the condition at any one time, although neurologists believe the figure could be as high as 10,000.

PSP is extremely difficult to diagnose and often people are initially given a diagnosis of Parkinson's Disease, due to the balance problems and slowness of movement that are often present during early symptoms.

CBD differs from PSP, with early signs often affecting one hand or one side of the body. For example, if CBD starts in one hand, there might be progressive numbness and loss of the use of the hand, with jerking fingers and slowness and awkwardness of movement.

We often use PSP as shorthand for both conditions. This guide will refer to conditions separately where there are distinct differences, as appropriate.



# Just diagnosed?



If you have just been diagnosed with PSP, you are probably experiencing all kinds of feelings and emotions, ranging from anger and disbelief, to relief that the condition has at last been given a name.



Chances are, you had probably never heard of PSP until the moment the diagnosis was given. Often, it takes a while for the news to sink in and now you may be wondering what to expect.



If you are feeling overwhelmed and uncertain right now, then rest assured that these are common and entirely normal reactions.

In the weeks and months after diagnosis you may experience a range of feelings, from anger and grief, and feelings of 'why me?' to gradual acceptance and a determination to enjoy life despite the challenges ahead.

Don't be too hard on yourself at this time. Give yourself permission to take one day at a time as you, and the people around you, come to terms with what's happening and work towards the future.

*Ensuring that you get the support you need is a joint effort involving:*

- You, your immediate carers and people close to you
- The PSP Association, health and social care, voluntary and charity organisations.

Everyone is different and it is only natural that you may worry about how you will cope as the condition progresses. The important thing to remember is that help is available during the course of your journey.

Remember that you do not need to go through this alone. Help and support is available via your GP and neurologist who will be able to answer your questions. You can also contact the helpline, information and advisory service for advice and support, and to talk through any concerns you may have.

# Living with symptoms



PSP can result in a range of symptoms that may impact on your balance and movement, vision, speech, swallowing and thinking processes. Early symptoms of PSP may include a sudden loss of balance, which causes you to fall backwards. Or you may experience difficulties with your eyesight, such as double vision, or difficulty in looking up and down.

Early signs of CBD may include a progressive numbness and loss of use in one of your hands, which gradually starts to affect the arm or leg on the same side of your body. You may find that you have difficulty when carrying out tasks that require you to use the small muscles in the affected hand – such as tying shoelaces.

It can be overwhelming to think about the various ways in which PSP or CBD may affect you in the future. Please bear in mind although there are a number of symptoms associated with PSP and CBD, you may not be affected by everything listed in this section.

Remember that if you need any advice on how to manage a particular symptom, your GP, neurologist, and other members of your healthcare team are there to help you.

If you have any questions regarding symptom management, you may also like to contact the helpline, information and advisory service.





# Cognition and mood



PSP is a challenging condition, and at times you may feel overwhelmed by your diagnosis, causing you to feel low in mood or depressed. However, you may also experience problems with cognition. Cognition refers to our mental processes and includes things like our ability to learn, reason and remember. It also refers to our ability to use and understand language.



If you are experiencing any problems with your cognition, you may feel that you lose confidence in situations that you used to find easy to deal with, or perhaps that you become more anxious than you used to. It is important to remember that PSP is causing this problem, and that you are not doing anything wrong.

The following information explains the various changes that can take place when cognition is affected. Please remember that symptoms vary enormously and that everyone's journey with PSP is different.

## Apathy

You may feel apathy, or a sense of withdrawing from everyday life. You may feel less enthusiastic about things that used to interest you, such as hobbies, or meeting up with friends and family. It can be hard to reignite the old spark if these feelings occur, but try to remember that it is PSP that is causing this change. Sharing your feelings with those around you may help them to understand what you are going through, and enable them to offer you the best support.

## **Impulsive behaviour**

You may sometimes find it hard to accept that PSP has limited your ability to do the things you always used to do. You may find that those around you are concerned about your behaviour, but this will often be because they are worried about your safety. For example, you may try to move around alone, even though you have poor balance. It can take some time to adjust to the fact that you need more help than you used to and at times you may feel very frustrated about the affects of PSP. You may also feel frustrated with those around you.

## **Mood swings**

You may occasionally have episodes of inappropriate laughing or crying. Try to remember that PSP can sometimes cause your reactions to be exaggerated.

## **Memory**

You may find that your memory is affected and that you find it difficult to learn new things or store new memories or information.

## **Language and thinking**

You may find it difficult to understand what is being said, or to find the words to express yourself and get your ideas across. You may also find it hard to sequence events in your head, so that getting conversation in the right order is more difficult than it used to be. You may also find it difficult to sequence actions, to the point that doing two things at once can become very confusing.

Sometimes you may have difficulty answering 'yes/no' questions, because 'yes' and 'no' become mixed up in your head. It is important for people around you to know if you are experiencing these issues so that they can support you effectively.

### **Behaviour**

Your family, friends and carers may notice that you do some things that are out of character. This may include becoming obsessed with certain things, repeating the same actions over and over. You may develop a sweet tooth and start to overfill your mouth with foods, which may cause concern to those close to you.

### **What can I do?**

Get as much support as you can. Be sure to discuss any cognitive changes with your GP or neurologist who can refer you for a specialist assessment to ensure that you and your family receive the best care and advice to help you manage these changes.

# Mobility and falls



Difficulties in movement and balance are a common feature of PSP. This is because PSP affects the areas of the brain associated with movement and balance control. In the earlier stages of PSP you may find that you move more slowly, or that your muscles become very stiff. This can affect your posture and gait, and can leave you feeling fatigued. It is important to be referred to a physiotherapist and occupational therapist as soon as possible after diagnosis to ensure that you have everything you need to help reduce some of the issues you may experience.

## Physiotherapist (Physio)

Physiotherapists help people to maintain good co-ordination, range of movement and mobility. They advise on exercises to help muscles, posture and minimise the stiffening of joints. They can also work with people as they adjust to changes in mobility. They might also be involved in supporting someone who has difficulties with breathing and coughing. Physios can also offer advice on aids that may help, such as walking frames or specially designed shoes.

Your occupational therapist and physiotherapist can advise you on all sorts of equipment that is available to enable you to remain as independent as possible, including:

- Grab rails or bars – firmly mounted bars are really useful in helping standing transfers from bed, shower and toilet
- Wet rooms or shower cubicles with side doors, so you can still enjoy a refreshing shower in safety.

### **Occupational Therapist (OT)**

The aim of the occupational therapist is to enable individuals to remain as independent and safe as possible in all activities of everyday life. They can advise on strategies to reduce the risk of falls, fatigue management, moving, handling and wheelchair provision. Occupational therapists can also offer advice on aids that can make daily life at home more manageable.

If you use a wheelchair, you may be provided with ramps in place of steps to help you get in and out of the house. If you live alone, or spend periods of the day by yourself, your occupational therapist can advise you on how to obtain a community alarm system, so that you can call for help if you fall over, or experience other issues that may affect your safety.

Always seek advice from your occupational therapist when considering purchasing any items of equipment, to ensure that it is safe for your needs, and that it will be helpful to you in the long term. This will prevent you spending money on items of equipment that may only be useful for a short time, or that are not safe for you to use. You may also find

that the equipment you need is available free of charge through your local services.

When you have PSP you may find that you fall over more. Falling over backwards is a distinct feature of PSP, and can cause serious injury, so it is important to minimise the risk of falls as much as you can.

If you have vision problems, this will also increase your risk of falling, particularly if you find it difficult to look down. Your occupational therapist, physiotherapist or local falls team, can offer invaluable advice to help keep you safe but there are some actions that you and your family can take to reduce risks. This may involve rearranging things and de-cluttering your home to minimise injury if you do fall. Look around the house to identify potential hazards and secure or remove the item if possible, for example, loose rugs.

If you have some cognitive issues, you may underestimate your difficulties with balance and stand up suddenly. This can lead to falls, but try to minimize this by asking your family and carers to place all your essential things close to hand so that you do not have to stand up to get them yourself.

# Fatigue and sleep



## Fatigue

Many people living with PSP experience fatigue. Fatigue is an overwhelming feeling of tiredness, lack of energy and exhaustion. It is often referred to as an invisible symptom, and can be felt physically, emotionally and mentally.

In the earlier stages of PSP, you may be affected by fatigue but still feel able to work or carry out many of the everyday activities of daily life. However, if fatigue is preventing you from doing the things you want to do then you may wish to review your activities to help maintain your energy levels and get the most out of life. Sitting down with family or friends and talking about the effects of fatigue may seem like a tiring idea in itself, but it can help you to work together to find ways of coping.

Think about how you feel during the day, and plan rest breaks that suit you. Some people benefit from several short breaks throughout the day, whereas others feel better after a longer rest. Do you feel tired about the same time each day? If so, then plan around this. For example you could let visitors know to avoid those times of the day where you really need to rest. If you are going out on a trip, plan around this to ensure that you are well rested before and after your excursion.

Whilst it is important to remain as active as you can, do take care not to overdo things, as this can lead to extreme fatigue. When you are feeling energised it can be tempting to fit in lots of activities. However, if this makes you feel more tired it may prevent you from doing the things you

really enjoy. Planning ahead is key to maximising your energy and getting the most out of life.

It can be really helpful to think about your daily tasks and start to prioritise them. Which tasks are urgent? Can you delegate any tasks to family or friends, so that you can conserve your energy for the things you really want to do? It can be hard to ask for or accept help, but remember that family and friends often relish the chance to help out in any way that they can. You may find it helpful to prepare a list of tasks that you are happy for other people to do.

If you are still working do speak with your occupational therapist who can advise you on how to make changes to your living or work spaces to help maximise your energy levels. This could involve small changes, such as keeping items that you use regularly in easy reach, through to various items of equipment that may help you to conserve your energy.

Taking care of your general health can also boost energy levels. Make sure that you are eating and drinking well, and if you are having any problems getting enough nutrients (perhaps due to swallowing difficulties) then your speech and language therapist and dietitian will be able to advise you on the best methods to manage this.

**See section on *Swallowing, eating and drinking*.**

## Sleep

As PSP progresses you may find that your sleeping pattern is affected. You may find it difficult to fall asleep or remain asleep, and you may experience changes in your body clock which cause you to be awake at night and asleep during the day. Making sure that you take regular visits outdoors for some gentle exercise and some fresh air can improve sleep cycles.

Sometimes sleep difficulties are made worse by other symptoms, such as pain, muscle spasms, restless legs, and anxiety or even as a side-effect of medication. You may find it helpful to discuss these issues with your GP or a member of your healthcare team, who can advise you on how to alleviate these symptoms.

They can also offer advice on methods of good 'sleep hygiene', which can help you to establish a regular and relaxing nighttime routine, leading to more restful sleep. In some instances, you may be invited to attend a sleep clinic.



# Pain



When you have PSP you may experience varying degrees and types of pain. Pain is more common in PSP than was initially presumed and can be present as a direct result of PSP, or as part of any other conditions that you are experiencing.

## Cramps and spasms

Most commonly you may experience muscle spasms or cramps as a result of muscular rigidity and stiffness. Or you may find that you experience headaches or a 'muzzy' or 'foggy' sensation in your head as a result of stiffness in your neck and back muscles. You may find the following treatments beneficial:

- Gentle massage of the area
- Muscle relaxant medications, which may be prescribed by your GP
- Passive exercises may help you to maintain a good range of movement in the joints (speak to your physiotherapist for more information)
- Applying specifically designed heat packs to affected areas may provide some comfort
- In some circumstances, your neurologist may suggest an injection of botulinum toxin (BOTOX) into the affected muscles, to reduce pain and spasm. The effects of the treatment last for approximately 3-4 months.



## Other causes of pain

You may experience pain from events that are secondary to having PSP. For example, pain from falls or pain from pressure sores that you may have developed as a result of poor mobility. You may also feel discomfort due to the effect that PSP has had on your posture, making it difficult for you to get comfortable.

Regardless of what is causing your pain, the most important thing is to seek medical attention. Pain may be relieved in a number of ways, from medications and injections, to passive exercises and use of specialist equipment to help you feel more comfortable. Talk to your GP, who may prescribe medications or refer you on to other professionals such as the physiotherapist, or the pain clinic.



# Speech and communication



Although everybody is affected differently, the majority of people with PSP will develop speech problems at some point as the disease progresses. This happens because the areas of the brain controlling the movement of the tongue, lips and throat are affected.

If you are experiencing any cognitive issues then this can also impact on your ability to communicate.

*Speech can be affected in various ways:*

- Your voice may become strained and harsh
- It may become quiet and fast, making it difficult for others to hear and understand you
- You may experience slurring of your words, particularly longer words, similar to the effects of excess alcohol.

If you are finding that your speech is affected, your GP can refer you to a speech and language therapist (SLT), ideally one who has previous experience of PSP.

## How cognitive changes can affect communication

If you have cognitive changes as a result of PSP this can also affect how you communicate. During conversation you may find that it takes you longer to process information, and therefore that your responses are slower. This can make others think that you are less interested in what they are saying, or they may assume that you do not want to take part. Letting people know about these challenges will ensure that they do not forget to include you in conversations, or to ask for your opinion.



You may also find it difficult to sequence your thoughts and this can make it harder for you to explain a sequence of events in the right order during conversation.

Furthermore, you may also find it difficult to sequence actions in your head, making it harder to carry out everyday tasks. It is important for people supporting you to understand this so that they are able to help by guiding you one step at a time if necessary.

You may find that doing two things at once, such as walking and talking, becomes less easy to do. Again, explaining this to people around you will help them to understand and support you more effectively.

If you are struggling with feelings of apathy, you may feel withdrawn from everyday life at times. This may be difficult for people around you to interpret, and it could be assumed that you are just taking longer to respond. If you feel able, explaining your feelings at such times may help to relieve pressure on you, as well as those around you.

**See section on *Cognition and mood*.**

### **Other factors affecting communication**

Because PSP affects the muscles, you may find that your facial expressions are reduced, or that problems with your vision make it harder for you to maintain eye contact with others. Explaining the situation will help them to understand that whilst you cannot look at them or may not be showing much change in facial expression, you are still interested in what they are saying.

## How can the speech and language therapist help?

The SLT can advise you on alternative techniques of getting your message across. They can also provide tailored guidance for carers, friends or relatives on how best to support you with any communication challenges. Try to have regular reviews with your SLT as your needs are likely to change.

Speech and language therapy may include exercises that target reduced speech volume, or increased speech rate. Or it may include simple techniques such as taking regular pauses to help make your speech easier to understand.

There is a huge range of techniques and devices to help support communication. Your SLT will assess you to find the best methods to support you based on your needs, abilities and preferences, but some examples of this include simple tools such as:

- Pen and paper
- Alphabet boards
- Communication charts.

Or more high tech solutions such as:

- Voice amplifiers
- Voice output communication aids.

The SLT may also advise you and your family, friends and carers on how to create your own systems of communication, such as the 'squeeze my hand' method suggested below.

### Top Tip

- If speech becomes difficult, another method might be useful. It works on a 'squeeze my hand' basis
- The carer simply 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.



# Swallowing, eating and drinking



PSP may affect your ability to swallow.

Difficulties with swallowing are quite common in PSP and can lead to:



- Coughing and choking when eating or drinking
- Taking a long time over meals or leaving food in the mouth
- Increased phlegm which is difficult to clear
- Weight loss
- Repeated chest infections as a result of food sliding into the lungs instead of the stomach (often referred to as 'aspiration').



Food and drink are such an integral part of our lives, helping us to maintain our health, whilst also providing an opportunity to socialize. If you are experiencing swallowing difficulties you may feel embarrassed about eating in front of others. Or you may feel that food is no longer enjoyable because it takes a long time to eat it, or because eating and drinking makes you cough, causing anxiety for you, your family, carers and friends.

If you experience any difficulty in swallowing, ask your GP for an urgent referral to your SLT, who can carry out a full assessment of your swallowing ability. The SLT can advise on swallowing techniques, and may also suggest the best consistency of food and drink, to make mealtimes easier and safer for you. The SLT works closely with the dietitian, who may suggest specially made food supplements for you, to help you maintain a healthy weight.

If swallowing is becoming very difficult, your healthcare team may suggest that you try an alternative method of eating, known as Percutaneous Endoscopic Gastrostomy (PEG). This is a method, which involves being fed via a small tube that is placed into your stomach, bypassing the need to eat and drink through the mouth. Remember, as with any medical intervention, the decision whether or not to have a PEG fitted is yours. For more information on PEG please contact the helpline, information and advisory service.

### **What else might affect your ability to eat and drink?**

Some of the other symptoms of PSP can also affect your enjoyment of meals. If you have problems with downward eye movement this can make it harder to see the food on your plate and get it to your mouth without spillage. Or if you have difficulty sitting comfortably or getting in a good position due to your posture or muscle stiffness, this can also have an impact on eating. Your occupational therapist can offer advice and equipment if appropriate to help you to get the best out of mealtimes.

If you are experiencing some cognitive issues, you may find that you suddenly have a very sweet tooth, or perhaps that you try to put too much food into your mouth at once. This can present an issue, particularly if you have some problems swallowing, and you may find that the people around you monitor you a little more closely at mealtimes, to keep you safe.

## Top Tips

- Talk to your GP if excess saliva or phlegm is presenting a problem at mealtimes. **See section on *Saliva, dry mouth and oral health*.**
- Chewing slow and difficult? Avoid things like thick cuts of meat or slow cook foods so they are tender
- Getting food stuck? Avoid dry and crumbly things. Add sauces to your meals or alternate mouthfuls of food with sips of water
- If you find that you are eating more slowly, consider purchasing a plate warmer to keep food warm and palatable.



# Saliva, dry mouth and oral hygiene



Saliva plays an important role in keeping the mouth healthy. It helps break down food and protects the mouth from drying out.



We all produce about a litre and a half of saliva every day, which we swallow frequently. However, if PSP has affected your ability to swallow effectively you may find that saliva builds up in your mouth, and is difficult to control.



Alternatively, you may find that you experience very thick saliva or mucus which you find difficult to swallow. Or perhaps your medications have left you with a very dry mouth.

It is vitally important to maintain good oral hygiene at all times, particularly whilst dealing with the challenges brought about by any changes in swallowing and saliva production.

## Too much saliva

Your healthcare team may be able to prescribe medication to help 'dry up' or reduce excess, watery saliva, but the following natural methods may also provide some relief.

Drinking ginger tea, sage tea or dark grape juice can help to reduce saliva production. However, if you have problems swallowing, be sure to consult with your speech and language therapist on the safest methods for you to drink.

Posture is important. Your granny was right when she told you to sit up straight at mealtimes! Try and keep your head upright too. Your occupational therapist can help if posture issues are affecting your ability to eat.

If you have swallowing difficulties you may naturally start to swallow less frequently. You may find that a swallowing reminder device can help you to manage your saliva more effectively by encouraging you to swallow more often. Your SLT will be able to advise you on reminder tools.  
**See section on *Swallowing, eating and drinking*.**

### **Sore Skin?**

- Dab excess saliva with tissues – it causes less irritation than rubbing
- Use a barrier cream, such as petroleum jelly to reduce soreness
- Sometimes, lip strengthening exercises can help. Again, your SLT or physiotherapist will be able to advise.

#### **Try these:**

- Push lips forward as if saying 'oo'
- Spread lips as if saying 'ee'
- Repeat 'oo' and 'ee' six times
- Puff air into the 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.

## Saliva too thick?

If you are finding that your saliva is too thick, the first thing to do is make sure you are drinking enough. Try and aim for one to two litres a day. Speak to your GP or SLT if swallowing difficulties are making it hard for you to drink enough fluids.

### Top Tips

- Avoid dairy products which can thicken mucus
- Keep caffeinated drinks and alcohol to a minimum
- Suck on crushed ice
- Pineapple contains an enzyme, which breaks down the protein present in thick saliva and mucus. Sipping pineapple juice or eating pureed pineapple can help to reduce these thick secretions.

## Dry mouth

If your saliva production is poor you may experience a dry mouth. This can lead to an unpleasant taste and coated tongue, increased dental decay, swallowing difficulties and dryness and cracking of tongue and lips.

Certain foods can affect saliva production. Ask your GP for a referral to a dietitian who can advise.

### *Other things that might help:*

- Drinking enough fluid – up to two litres every day. Taking frequent sips of water helps prevent the mouth from drying. Speak to your GP or SLT if swallowing

difficulties are making it hard for you to drink enough fluids

- Avoiding sugary foods and drinks that may damage your teeth
- Using lip balm or petroleum jelly to moisten lips, and removing dentures at night
- Your GP may be able to prescribe gels or sprays to help with dry mouth.

## Teeth

Looking after your teeth is essential and reduces the risk of other oral health problems. If you find brushing difficult due to other symptoms that you may be experiencing, ask your dentist for advice. There is a wide range of products available to help clean the teeth effectively, including curved toothbrushes, dental floss, mouthwashes and special brushes that clean between the teeth. Where possible, ensure that you have regular check-ups with your dentist to help maintain good oral health.



# Vision



PSP commonly affects the eyes, and you may experience visual problems that cannot be corrected with glasses. If you have CBD, problems with visual disturbances are less common.

*The most common symptoms are:*

- Double vision
- Tunnel vision, where the field of vision is reduced
- Blurred or misty vision
- Slow, jerky eye movements that can make it hard to read from one line to the next, or look from one point to another. When this happens you may find it difficult to make eye contact with others. Explaining the situation will help them to understand that whilst you cannot look at them, you are still interested in what they are saying
- Difficulty looking down. This can cause problems at mealtimes and increase the risk of falls
- The inability to deal with bright lights
- Involuntary eyelid closure, difficulty opening the eyes.

If visual issues are making daily life difficult, ask you GP to refer you to the relevant eye specialist, for professional assessment and, where possible, treatment.

If you are experiencing visual problems then this can present a safety issue, especially when walking around. Your OT or local falls team may be able to advise you on the best way to create a safe environment.



Furthermore, if you are registered as having sight problems you may be eligible to receive talking books and newspapers via your local council, the RNIB, or other organisations.

### Top Tips

- If double vision is a problem, putting a patch over one eye or taping over one lens can help
- If you are unable to look down then you may find prism glasses helpful. You can obtain these from the PSP Association. If you wear prescription glasses your optician may be able to supply prism film. Please note, it is dangerous to try to walk in prism glasses.
- If bright light is a problem, wraparound sunglasses or tinted lenses can help
- Botox injections, (botulinum toxin) are sometimes used to alleviate problems with opening and closing the eyelids. Ask your specialist for advice
- If you are not always able to close your eyelids, your eyes may become dry and sore. Your GP may be able to advise you on eye sprays or eye drops to help alleviate this.

## Useful Contacts

*The services provided below are either free or low-cost:*

**Your local library:** offers a wide range of spoken cassettes and CDs

**Calibre Cassette Library:** Unabridged books on cassette

Telephone: 01296 432 339

Website: [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

Telephone: 020 7407 9417

Website: [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

Telephone: 0845 762 6843

Website: [www.rnib.uk/talkingbooks](http://www.rnib.uk/talkingbooks)

**Talking Newspaper Association:** National newspapers on cassette tape and in electronic form

Telephone: 01435 866 102

Website: [www.tnauk.org.uk](http://www.tnauk.org.uk)

# Bladder and bowel



When you have PSP you may find that you develop some problems with constipation, reduced bowel control, and urinary issues.

## Constipation

If you are less able to move around due to reduced mobility, you may find constipation becomes more of a problem for you. Constipation may also occur as a side effect of your medication, or perhaps because you are eating and drinking less. If you are experiencing constipation you will need to seek advice from your GP. However there are some measures you can take yourself to help reduce the occurrence of constipation.

### *Keep digestion healthy by:*

- Ensuring that there is plenty of fibre in your diet – include vegetables, fruit and whole grain products
- Drinking plenty of fluids throughout the day. If swallowing is an issue, then ask your GP for advice on keeping up fluid intake
- Exercising where possible, if it is safe to do so – ask your physiotherapist for guidance
- Allowing enough unhurried time to visit the loo
- Alerting your GP about any problems so they can monitor the situation.



## Bladder

You may find that you have a frequent and sudden urge to pass water, or that you have difficulty starting to pass water even when your bladder is full.

Your GP can offer advice and double check that there is no infection. They can also offer a referral to a continence adviser who will be able to offer in-depth advice and reassurance.

### Top Tips

- Drink plenty of fluids, especially water, but keep stimulants like tea and coffee to a minimum in the evening
- Wear clothes with elasticated waists or hook and loop fastenings make getting to the toilet easier
- Ask your occupational therapist for advice on toilet fittings, such as raised seats and grab rails.

There are plenty of discreet aids available for incontinence problems, ranging from pads to absorbent sheets. In some circumstances members of your healthcare team may suggest that a catheter is the best option for you, especially if you have difficulty in emptying your bladder fully. Don't be embarrassed to mention any problems you have, and remember that the healthcare team you deal with have seen many similar situations before.



# How the PSP Association can help



## The PSP Association Helpline, Information and Advisory Service



We offer advice, information, practical and emotional support to people living with PSP. Sometimes you may feel like you could do with a listening ear. We know how reassuring that can be and encourage you to get in touch with our helpline, information and advisory service.



Our telephone and email service is completely confidential and we aim to respond to all enquiries within 24 hours (during normal office hours). Our opening hours are Monday to Friday from 9am until 5pm.

Telephone: 0300 0110 122

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

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

We often experience busy periods to the service and if we do not answer straight away then we may be taking another call. Please be reassured that if you leave a message we will return your call as soon as someone is available.

*Please note we are unable to return calls to telephone numbers with an anonymous call-barring system.*

Telephone calls are charged at the cost of a local rate call (depending on your service provider). If you are

calling from either a mobile or a landline that has inclusive minutes, your call will be free (but the call will use your allocated minutes).

### **Local Groups**

Our network of local groups is growing. These are opportunities for people living with PSP/CBD, carers, family and friends, health and social care professionals, to share information, encouragement and refreshments.

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

### **Specialist Care Advisers**

Our team of Specialist Care Advisers (SCAs) work to ensure that people affected by PSP have access to good local support. They focus particularly on more complex cases and work to ensure there is a local keyworker to coordinate care wherever possible (or acting as such where one is not available).

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

### **PSP Website**

Our website offers accurate, timely and relevant information on all aspects of PSP, including the latest news on research and events [www.pspassociation.org.uk](http://www.pspassociation.org.uk)

## **PSP Forum**

We have our own forum, which can be accessed via <http://psp.healthunlocked.com>

The forum gives individuals the opportunity to connect with others affected by PSP and those working with the condition. It's also an opportunity to find out what other people living with PSP are doing and thinking.

## **How to contact us:**

Telephone: 0300 0110 122

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

The PSP Association

PSP House

167 Watling Street West, Towcester

Northants NN12 6BX

*"I am so glad that the PSP Association has introduced this new service. I contacted the helpline today for the first time. It's a marvellous service. The person I spoke to understood my situation and was helpful and knowledgeable."*

**Susan**