Progressive Supranuclear Palsy
PSPA

Your Personal Guide to PSP

Working for a World Free of PSP

Section 1

Introduction to PSP and CBD

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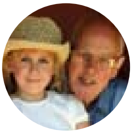
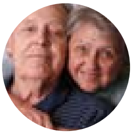
PSPA Progressive Supranuclear Palsy

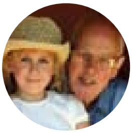




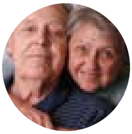
Introduction to PSP and CBD

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 Cotico 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:

- If 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.**

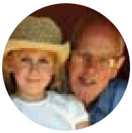
PSP is associated with the over production of a protein called 'tau' in certain areas of the brain. Researchers are still unsure as to the precise cause of PSP but it is thought to result from a combination of genetic and environmental factors.

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.

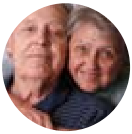
PSP is extremely difficult to diagnose and often people are initially given a diagnosis of Parkinson's Disease, due to the balance problems and slowness of movement that are often present during early symptoms.

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.

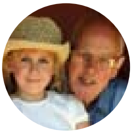
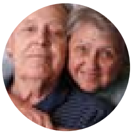
Don't be too hard on yourself at this time. Give yourself permission to take one day at a time as you, and the people around you, come to terms with what's happening and work towards the future.

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.

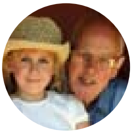
Early signs of CBD may include a progressive numbness and loss of use in one of your hands, which gradually starts to affect the arm or leg on the same side of your body. You may find that you have difficulty when carrying out tasks that require you to use the small muscles in the affected hand – such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

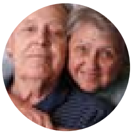
It can be overwhelming to think about the various ways in which PSP or CBD may affect you in the future. Please bear in mind although there are a number of symptoms associated with PSP and CBD, you may not be affected by everything listed in this section.

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.

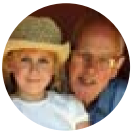
Sometimes you may have difficulty answering 'yes/no' questions, because 'yes' and 'no' become mixed up in your head. It is important for people around you to know if you are experiencing these issues so that they can support you effectively.

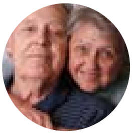
Behaviour

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.

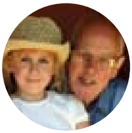
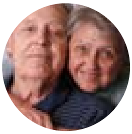
If you use a wheelchair, you may be provided with ramps in place of steps to help you get in and out of the house. If you live alone, or spend periods of the day by yourself, your occupational therapist can advise you on how to obtain a community alarm system, so that you can call for help if you fall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

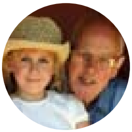
Taking care of your general health can also boost energy levels. Make sure that you are eating and drinking well, and if you are having any problems getting enough nutrients (perhaps due to swallowing difficulties) then your speech and language therapist and dietitian will be able to advise you on the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

Sleep

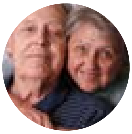
As PSP progresses you may find that your sleeping pattern is affected. You may find it difficult to fall asleep or remain asleep, and you may experience changes in your body clock which cause you to be awake at night and asleep during the day. Making sure that you take regular visits outdoors for some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

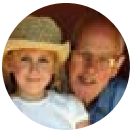
Most commonly you may experience muscle spasms or cramps as a result of muscular rigidity and stiffness. Or you may find that you experience headaches or a ‘muzzy’ or ‘foggy’ sensation in your head as a result of stiffness in your neck and back muscles. You may find the following treatments beneficial:

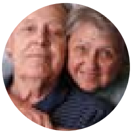
- Gentle massage of the area
- Muscle relaxant medications, which may be prescribed by your GP
- Passive exercises may help you to maintain a good range of movement in the joints (speak to your physiotherapist for more information)
- Applying specifically designed heat packs to affected areas may provide 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.

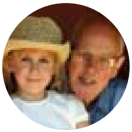
Or more high tech solutions such as:

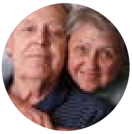
- Voice amplifiers
- Voice output communication aids.

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.

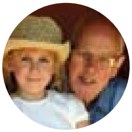
What else might affect your ability to eat and drink?

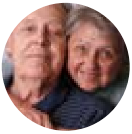
Some of the other symptoms of PSP can also affect your enjoyment of meals. If you have problems with downward eye movement this can make it harder to see the food on your plate and get it to your mouth without spillage. Or if you have difficulty sitting comfortably or getting in a good position due to 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.

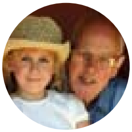
Other things that might help:

- 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

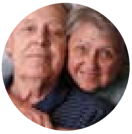
- Avoiding sugary foods and drinks that may damage your teeth
- Using lip balm or petroleum jelly to moisten lips, and removing dentures at night
- Your GP may be able to prescribe gels or sprays to help with dry mouth.

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:

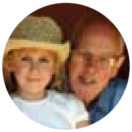
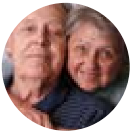
Your local library: offers a wide range of spoken cassettes and CDs

Calibre Cassette Library: Unabridged books on cassette
Telephone: 01296 432 339
Website: www.calibre.org.uk

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

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

Talking Newspaper Association: National newspapers on cassette tape and in electronic form
Telephone: 01435 866 102
Website: 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

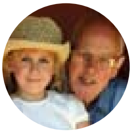
You may find that you have a frequent and sudden urge to pass water, or that you have difficulty starting to pass water even when your bladder is full.

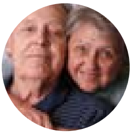
Your GP can offer advice and double check that there is no infection. They can also offer a referral to a continence adviser who will be able to offer in-depth advice and reassurance.

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

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

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

The PSP Association
Margaret Powell House
415a Midsummer Boulevard
Milton Keynes MK9 3BN

"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

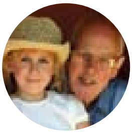
Section 2

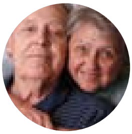
Living with PSP

This section includes:

- Health and Social Care Professionals
  Who they are and how they can help
- Advance care planning
- Statutory Benefits
- Driving
- Complementary therapies
- Holidays
- How the PSP Association can help

Progressive Supranuclear Palsy
PSPA



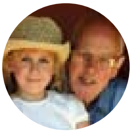


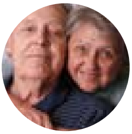
Living with PSP

Introduction

In this section we aim to offer plenty of practical information, including details of some of the healthcare professionals who may be involved throughout the course of your illness, advice on how to help manage decreasing mobility and information on statutory benefits that might be available.

At the time of publication in 2013, there are on-going welfare reforms. As the benefits system is already complex, we are signposting you to the organisations that have specific, relevant and up to date information.





Health and Social Care Professionals

Who they are and how they can help

Most people will see a number of health professionals during their illness. PSP is a rare disease and because of this most GPs will only come across one person with the condition during their working life.

To help you, here is a thumbnail description of the health and social care professionals who may be involved in your care. As PSP varies greatly from person to person, you won't necessarily meet all of them, and the list isn't meant to be exhaustive. Health professionals involved in your care may include:

General Practitioner (GP)

Your GP will be the primary carer. This means that they are responsible for looking after your health. GPs deal with an enormous range of health concerns, normally as part of a practice that offers all kinds of supporting services. If a GP cannot deal with a problem, they will refer you to other services, such as a hospital for tests or to a specialist consultant.

At some point during their illness many people with PSP will see:

Multi-Disciplinary Team (MDT)

This is a group of health and social care professionals involved in someone's care. They work together to co-ordinate care and support. The MDT also plan treatment tailored to the person's individual needs.

Neurologist

Neurologists specialise in the diagnosis, symptom management and on occasion the continuing assessment and care of people living with diseases of the central and peripheral nervous systems and the muscles. They may also be involved in research into conditions such as PSP.

Occupational Therapist (OT)

The aim of the occupational therapist is to help you continue daily routines with as much independence as possible. They can advise on strategies to reduce the risk of falls, fatigue management, moving, handling and wheelchair provision. They can also offer advice on aids that can make daily life at home more manageable, such as grab rails and wet rooms.

Dietitian

Dietitians work closely with your speech and language therapist to advise on appropriate diet, help you maintain a healthy weight and offer advice on food consistency where swallowing may be difficult.

Orthoptist and Ophthalmologist

Orthoptists investigate, diagnose and treat defects of binocular vision and abnormalities of eye movement. They work very closely with ophthalmologists, who helps with the management of the symptoms. This may involve eye exercises, special lenses or eye surgery.

Physiotherapist (Physio)

Physiotherapists will advise you how to maintain good posture, muscle strength, and reduce the risk of falling. In addition they will help to minimise the stiffening of joints and help you to adjust to changes in mobility by providing advice on aids that may be of benefit. The physiotherapist may also be involved in supporting you should you experience difficulties with breathing and coughing.

Your carer may also benefit from advice from the physiotherapist on the safest way to assist you with your day to day activities.

Social Worker and Care Manager

Social workers and care managers provide support to enable access to appropriate care for both yourself and your carer. They also offer advice on regular respite breaks and residential care as well as how to access appropriate local services.

Speech and Language Therapist (SLT or SALT)

Speech and language therapists are able to carry out assessments if you are experiencing problems with communication and can offer advice on suitable communication aids.

They also work very closely with your dietitian should you experience swallowing difficulties.

District Nurse (DN)

District nurses manage health care for people in their own homes or in residential care. They offer advice on a wide range of issues, from palliative care, equipment provision and medication support. Community nurses work alongside them visiting people in their homes and providing nursing care (not personal care). This would include things such as the monitoring of your care needs. Both nurses have links with GP surgeries, the palliative care team and they provide follow-up care when people have come home from hospital.

Community Pharmacist

Based in the local pharmacy, they are responsible for the sale and supply of prescription and over the counter medicines. They are also available to offer advice on medicines, symptoms and general health matters.

Community Matron

Community matrons are community based senior nurses who work with people who have long term and complex conditions. They are involved in co-ordinating care and ensuring people have access to services.

Community Psychiatric Nurses (CPNs)

CPNs are nurses trained in mental health. They work with people who are experiencing depression, anxiety and dementia as well as other mental health conditions. They offer practical advice on a range of issues from medication to coping skills.

Continence Adviser

These are usually registered nurses specialising in supporting people at home with any bladder and bowel issues. They offer advice on medications, continence supplies and equipment. They liaise with other health and social care professionals including district nurses and GPs.

Clinical Psychiatrist

They specialise in the diagnosis and treatment of mental illness, prescribing and monitoring medication needs for people with mental health conditions such as anxiety, depression and addiction. They work with multidisciplinary teams to support people with mental illnesses, including dementia.

Clinical Psychologist

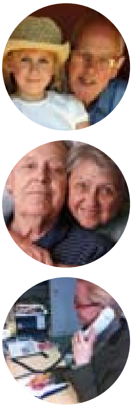
These experts support people experiencing severe psychological distress. Access to a psychologist can be made through a psychiatrist or palliative care team. Among the treatments they offer may be psychotherapy, cognitive behavioural therapy and relaxation techniques.

Geriatrician

Geriatricans specialise in the care of the elderly and deal with a wide range of conditions. They also offer advice on symptom management, access to community services and advanced planning.

Palliative Care Team

This group of specialists is likely to include doctors, nurses, social workers, dieticians, complementary therapists and chaplains. Together, they address the physical, spiritual and social concerns that arise with advanced progressive illness. Between them they can offer support for symptom management and planning for the end stages of illness. They will support the person affected and people close to them. The palliative care team will usually be linked to a local hospice that may also provide day care and in-patient respite care.



Advance care planning

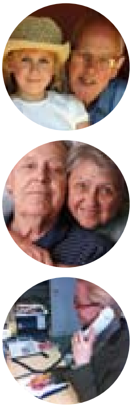
If the diagnosis of PSP is fairly recent, it might seem odd to have to give thought to how you would like to be cared for in the future. But it is important to look at advance care planning early on.

Advance care planning is entirely voluntary and no-one has to do this unless they want to. It is a chance for you and the people who provide your care – for example, doctors and family members – to discuss the way you would like your care to proceed as the condition progresses.

It’s an opportunity for you and your carers to express thoughts, preferences and wishes about your future care. It is a personal process, unique to you, the person with PSP.

PSP is a progressive illness, where the symptoms change over the course of time. That is why it can be helpful to both you and your carers to talk about your wishes – to help make plans. Not everyone will want to do this so remember whatever route is chosen, that is fine.

See section on *Advance care planning* in Section 4 of this guide.



Statutory benefits

If you have worked hard all your life it might feel uncomfortable to apply for support and financial benefits.

The benefits system is going through a period of welfare reform at the moment. As things are changing fast and are quite complex, use this section as a guide to signposting you to the information you need.

Sometimes the number of forms can seem overwhelming and the process isn't helped by the varying assessment standards and availability of support.

Top Tips

Once you are 'in the system' then things become a lot easier

- There is a lot of help available to assist you
- Many of the forms consist of 'tick' boxes and are not as daunting as you might think.

Advice

There is plenty of local advice available, including:

- Your local branch of Carers UK.
  Telephone: 0808 808 7777
  Website: www.carersuk.org to find your local carers service
- Your nearest Citizen's Advice Bureau
- Your local branch of Age UK
  Website: www.ageuk.org.uk

- The various Government Helplines, stated on the application forms
- *The Disability Rights Handbook*. Published by the Disability Alliance 0207 250 3222, Website: www.disabilityalliance.org
- The PSP Association Helpline, Information and Advisory Service. Telephone: 0300 0110 122 Email: helpline@pspassociation.org.uk

Health Benefits

Regional variations

Eligibility for various benefits varies from place to place in the UK – for example, people in Wales are eligible for different benefits to people in England. Always talk to your GP in the first instance, as they will have up to date information.

You *may* be entitled to:

- Exemption from prescription charges
- Free eye tests, free or subsidised glasses or contact lenses
- Free talking books and newspapers.

VAT Relief

People with PSP should not have to pay VAT on equipment or services related to their disability, including disability aids such as lifts and adjustable beds, and home adaptations to help with their disability.
Check HRMC for up to date information.
Website: www.hmrc.gov.uk

Council Tax Reduction and Benefits

You may be entitled to a reduction or to help paying your Council Tax (Rates in Northern Ireland).

For further information search for *Council Tax Reduction* at www.gov.uk or www.nidirect.gov.uk (Northern Ireland).

Housing Benefit

You may be entitled to Housing Benefit for a number of reasons. For further information search for *Housing Benefit* at www.gov.uk. or www.nidirect.gov.uk (Northern Ireland).

Housing Adaptations and Equipment

The owner, tenant or landlord can apply for financial help with housing adaptations and equipment. Maximum limits vary depending on which area of the UK you live in.

For further information search for Financial help or the *disabled/ home and housing* at www.gov.uk or www.nidirect.gov.uk (Northern Ireland)

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.

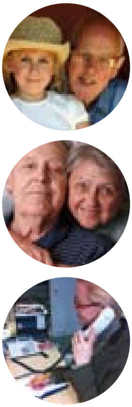
- Turn2us provide a comprehensive list of charity help available.
  Website: www.Turn2us.org.uk

The Disability and Carers Service

The Disability and Carers Service is part of the Department for Work and Pensions (DWP). It provides financial support for customers claiming disability benefits and their carers – for example, Disability Living Allowance and Carer's Allowance. Visit: www.dwp.gov.uk for more information

When completing forms

- Be realistic rather than optimistic
- Do not say the person can do something when in reality it causes them pain or exhaustion
- Focus on your worst day and fill in the form on that basis – that's when you need the help
- Try to give a clear picture of the situation. For example, if the question is: 'Can you wash and dress?' Don't just say 'Yes' if the real answer is 'It takes me two hours with frequent rests and I need 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 application form handy as you may receive a phone call to confirm details and it is important that you provide the same information as the application form
- It may help to keep a diary of activity, to have something to refer to.



Driving

There may be a point when you are no longer able to drive. This loss of freedom can be very hard to accept, especially if you have always used a car.

Has PSP affected your driving ability? Can you judge distances accurately? Do you experience confusion regarding the rules of the road? Are you able to physically and mentally act quickly in the event of any emergency? Ultimately you have to consider your safety, and the safety of those around you.

If you are a driver, you must report your diagnosis to the DVLA as soon as possible. This does not automatically mean that your driving licence will be withdrawn immediately. The DVLA may ask you to take part in a driving assessment before making a decision.

For further information search for *DVLA medical enquires* at www.gov.uk or www.nidirect.gov.uk (Northern Ireland).

Please Note: You must advise your insurance company of any diagnosis or change in condition that may affect your ability to drive, as failure to do so may invalidate your policy.

Top Tip

Notify the DVLA as soon as possible after diagnosis. It is a criminal offence not to do so.

Driver Licensing Enquires

Telephone: 0300 790 6801
Textphone: 0300 123 1278 Fax: 0300 123 0784
Monday to Friday 8am to 7pm Saturday 8am to 2pm

Driving options

- If someone else can drive, it may still be possible for you to get out and about. If getting in and out of the car is difficult for you, adaptations may help. Ask your occupational therapist for advice
- There may be local transport schemes, such as volunteer drivers, in your area. To find out what is available contact:

  The Community Transport Association

  Telephone: 0845 130 6195
  Website: www.ctauk.org (UK)

  Website: www.communitytransport-ni.com (Northern Ireland)
- **Regional Driving Assessment Centres** aim to help people maintain mobility through driving. For more information, and to find your nearest Driving Assessment Centre, visit: www.rdac.co.uk or contact: Regional Driving Assessment Centre, Unit 11, Network Park, Duddeston Mill Road, Saltley, Birmingham B8 1AU. 0845 337 1540, email: info@rdac.co.uk
- **Motability**

  This scheme allows people on certain benefits to enjoy a new car, scooter or powered wheelchair without the worry of owning and running one. Today, around 600,000 disabled people and their families benefit from the scheme

  Check eligibility by contacting Motability on: 0845 456 4566 or www.motability.co.uk for more information.

Top Tips

Blue Badge Scheme

These are issued by your local authority. They offer the use of disabled parking bays and many other parking concessions. Some cities, including London, operate their own schemes, so check locally

If you receive the higher rate mobility component of Disability Living Allowance (DLA), or the enhanced rate mobility component of Personal Independence Payment (PIP) you do not have to pay road tax. If you receive the standard rate of PIP you are entitled to a reduction of 50%.

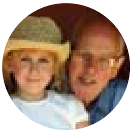
For further information search *Vehicle exempt from car tax* at www.gov.uk or nidirect.gov.uk (Northern Ireland).

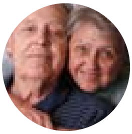
Disabled Person's Railcard

This offers a third off most fares. Check with your local station regarding eligibility
www.disabledpersons-railcard.co.uk

Bus Discounts

Your social services department will advise on any local bus discounts available.





Complementary therapies

Some people affected by PSP like to try complementary therapies in addition to the help and support they receive from conventional medicines.

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

Before having any complementary therapy, discuss it with your GP to ensure that it is the right option for you.

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

Most complementary therapies, as the name implies, 'complement' rather than replace modern medicine. The NHS is starting to acknowledge that complementary therapies may provide some benefit.

Some hospices provide short courses of complementary therapy free of charge. However, if this is not available then your GP may be able to refer you to a reputable therapist in your area, Please be aware that most complementary therapists will charge for their services.

What might help?

It is 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 and their carers. Complementary therapies may provide you with relief from symptoms associated with:

- Tension/stress
- Anxiety/panic attacks
- Depression
- Pain
- Musculoskeletal problems
- Constipation
- Temperature control
- Sleeplessness/fatigue.

Finding a therapist

Always use accredited therapists. Check the individual websites for information. 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 someone with PSP will need an understanding of the disease and any other conditions the person with PSP might be experiencing.

Acupuncture

Acupuncture is part of the ancient and complex system of traditional Chinese medicine.

The British Acupuncture Council (BAcC), 63 Jeddo Road,
London W12 9HQ.
Telephone: 0208 735 0400.
Website: www.acupuncture.org.uk

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.

The Shiatsu Society (UK), Eastlands Court, St Peters Road,
Rugby, Warwickshire CV21 3QP.
Telephone: 0845 130 4560
Website: www.shiatsusociety.org
Email: admin@shiatsu.com

Reflexology

Reflexology is based on the principle that all the organs of the body have corresponding reflex points on the feet.

The Association of Reflexologists, 5 Fore Street, Taunton,
TA1 1HX
Telephone: 01828 351010
Website: www.aof.org.uk

Aromatherapy

Aromatherapy uses essential oils from plants which are applied to the skin, mixed in water or inhaled.

The International Federation of Aromatherapists,
20A The Mall, Ealing, London, N5 2PJ
Telephone: 0208 567 2243
Website: www.ifaroma.org

Massage

Massage stimulates and energises the body and leads to a feeling of calmness and relaxation.

The British Massage Therapy Council (BMTC), 17 Rymers Lane, Oxford. OX4 3JU.
Website: www.bmtc.co.uk

Reiki

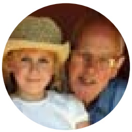
Reiki was developed in Japan in the 1800's and the theory is based on practitioners being able to draw on and channel healing energies from the patient's own body.

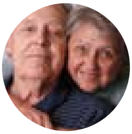
The UK Reiki Federation, PO Box 1785, Andover. SP11 0WB.
Telephone: 01264 773774.
Email: enquiry@reikifed.co.uk

Relaxation and meditation

Meditation techniques are believed to encourage simple healing and spiritual growth. There are many centres and health clubs throughout the UK offering meditation.

Holidays





Holidays can provide a vital break – and a welcome change of scene. It is important to be realistic about your level of disability and any extra requirements you have when planning a holiday. But the good news is that there is 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.

It is a good idea to talk to your GP to seek advice on fitness to travel and to ensure that you have enough of your medications to take with you. Before leaving, check out access to toilets en route, particularly on planes if travelling long distances.

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.

You may wish to make contact with your travel company 48 hours before departure to check that your arrangements are recorded and in place. If you have room in your suitcase you may wish to pack *'Your Personal Guide to PSP'*.

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

Top Tip

Discuss any holiday plans with your GP first and don't plan too far in advance as some symptoms can change quite quickly.

Funding assistance

Some charities will offer financial support for holidays. Turn2Us is a charitable service which helps people access money that may be available to them - through welfare benefits, grants and other help.
Website: www.turn2us.org.uk

Saga Respite for Carers Trust

Saga Respite for Carers Trust may be able to help with the cost of a much-needed holiday for carers and their companions.

Eligibility criteria:

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 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.

Vitalise holidays

Vitalise is a national charity providing short breaks and holidays (respite care) for people with physical disabilities and their carers.
Telephone: 0303 303 0145
Website: www.vitalise.org.uk

General help and advice

These organisations can help you to tailor your holiday to meet your needs.

- ***Rough Guide to Accessible Britain***

  Full of ideas for accessible days out across the UK. This book is free for all blue badge holders.
  Telephone: 0800 953 7070. It can also be downloaded from the website: www.accessibleguide.co.uk

- **Tourism For All**

  Provides advice on accessible holiday accommodation
  Telephone: 0845 124 9974
  Website: www.tourismforall.org.uk

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

  Visit www.radar.org.uk for up to date information or to obtain a RADAR Key which will open most public disabled toilets

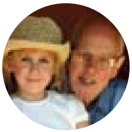
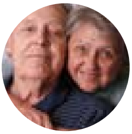
- **DPTAC**

  The Disabled Persons Transport Advisory Committee (DPTAC) is an independent body advising Government on the transport needs of disabled people.
  Website: www.dptac.independent.gov.uk

Transport

Information on all types of public transport for people with disabilities is available.

For further information search for *transport-disabled* at www.direct.gov.uk or www.nidirect.gov.uk (Northern Ireland).


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

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.

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Telephone: 0300 0110 122
Email: helpline@pspassociation.org.uk

The PSP Association
Margaret Powell House
415a Midsummer Boulevard
Milton Keynes MK9 3BN

"How professional the PSPA have been – a Gem".

Steve

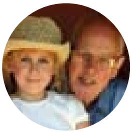
Section 3

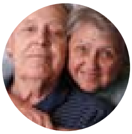
Caring for someone with PSP

This section includes:

- The stages of caring
- Staying healthy
- Practical help – Carer's Assessment
- Getting help
- Balancing work and caring
- How the PSP Association can help

Progressive Supranuclear Palsy
PSPA





Caring for someone with PSP

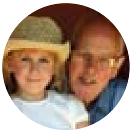
Introduction

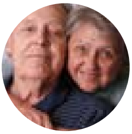
This section has been specially compiled to offer support and advice for anyone caring for someone living with PSP.

As you know, the condition affects people differently and every case is unique. Similarly, every carer approaches this often unexpected role in their own way. You might not see yourself as a carer – you might think of yourself as 'just' a partner, relative, friend or good neighbour - but we use the term to describe people who are helping others live with PSP.

However there are many areas of common ground that affect the majority of carers. Sometimes, just knowing that your feelings are normal is all the reassurance you need.

The stages of caring





Caring for someone with PSP

Caring for someone with PSP is likely to be a new role for you, one you never expected to take on. If you are just finding your feet, give yourself plenty of time to adjust. This is probably new for both of you, so work together to enable quality of life as the condition progresses.

Like many things in life, there are stages to caring. Just as living with PSP is like travelling along a road, caring is a journey in its own right. There will be times when you feel confident in your new role and moments when you worry that you are not doing things right. The main thing to know is that all these feelings are perfectly normal and have been experienced by many others before you. Some people think that there are clear stages to the caring process, but others don't feel this at all.

It might be useful to know what some of these stages are like – but remember everyone is different and some, all or none of these reactions and feelings may apply to you.

Shock

When you first step out on the road to caring, you might feel some initial shock and worry about the uncertainty ahead. You might feel that life has changed and things will never be the same again. But often, in the early days help and support – especially from friends and people close to you – is forthcoming. This can help prevent you feeling quite so overwhelmed by the new situation you find yourself in.

Sometimes you might feel scared, angry, sad, lost or anxious. You will probably find that these feelings fade as you get used to the new situation. At the very beginning of the caring process, some people make big decisions, like giving up their job or planning to move house. Often, it is wise to give yourself time to adjust before you do any of these things.

Loss

Many carers do tell us they have feelings of loss. When someone is diagnosed with PSP it is likely that it will gradually affect their future plans. Carers can experience feelings of loss in different areas of their lives, such as loss of their long-intended plans, loss of freedom, and sometimes feelings that they have 'lost' certain aspects of their relationship with the person affected by PSP, due to their role as a carer.

All these feelings are quite normal and you will probably find that you gradually learn to adapt and adjust to the new situation and are able to seek positive outcomes and make new, if different, plans.

Reality

This is when you start to adjust to your new-found role and gradually work towards some kind of routine that works for both you and the person with PSP. Again, there can be moments when you might feel guilty or resentful.

Some carers find that they let things go that they often used to enjoy, such as hobbies and a social life. Although it is tempting to do this, and easy to understand why it can happen, it is best not to make any hasty decisions. This is

the time when carers can start to feel tired and feel that caring is dominating their life. It's really important to look after your own health and eat a good diet.
For further information *see page 6 of this section.*

Sometimes, it's easy to neglect your own needs because you feel you have to put all your energies into caring. Try not to take on too much and if you feel under strain remember to talk to your GP who can monitor your own needs.

Acceptance

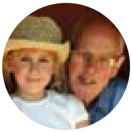
There is no clear timeline for when you reach the point of acceptance of the situation. If you have been a carer for a while now, you have experience of caring and some idea of what to expect on a day-to-day basis. Because PSP is a progressive condition, you have probably learned to deal with, and accept changes as they occur. It's good to be able to recognise if things are starting to feel harder to deal with, or if a new and extra level of care is now required.

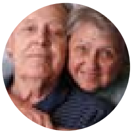
But it's important to remember to try and get all the help and support you can. If you have not already, seek a carer's assessment.
For further information *see page 8 of this section.*

When the going gets tough…

It's only natural that now and again, you might feel as if things aren't going well. You might feel overwhelmed by the responsibilities of caring and guilt at these feelings. if this happens try to keep in mind that:

- Everyone has off days so don't be too hard on yourself
- A change of scene can work wonders, even if it only means getting out of the house for a quick walk round the block
- Try and get enough sleep at night
- If possible, do some exercise – a walk, swim or even a class can help lift your mood
- Don't overdo your to-do list. Too much pressure can make you feel overwhelmed
- Talk to people who help you to feel positive – on the phone, online or face-to-face
- Have a rough plan of the day's expectations, but be flexible – accept that events can change the course of every day
- Can family and friends help out? Have a list of chores ready to delegate. Often, friends and family are only too willing to help out in any way they can.





Staying healthy

As a carer you instinctively know that staying well is in your best interests – as well as for the person with PSP. Caring can be a very rewarding role but it can also be tiring. Making sure you eat well and looking after your health needs is as important as looking after the person you are caring for.

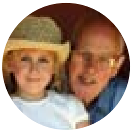
Tell your GP that you are a carer. The Government requires surgeries to have a register of carers and you should get priority when arranging appointments.

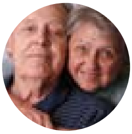
Consider asking your GP to refer you for advice on correct moving and handling techniques. Your back may well be a critical part of your caring toolbox and it needs protecting!

It is tempting to put your own health needs low on what seems like a very long list, but if you are in good shape – physically and emotionally – you will be better able to fulfil your role as a carer.

- Try and eat healthily, ensuring you have a good mix of protein, carbohydrates, fruits and vegetables. And remember each day is different. Sometimes you will be able to cook a meal from scratch, other times you will be relying on convenience foods. Be flexible
- Enjoy your food. Sometimes you might find mealtimes quite challenging, especially if the person you are caring for has swallowing difficulties. It might be worth spending a little time planning new or different menu choices

- Try and get some exercise every day – even if it is just a walk to the post box or a stroll round the supermarket
- Treat yourself every now and again. Carers often feel guilty about thinking of themselves but it is essential for you to think of yourself in order to be able to manage your role as carer.





Practical help - Carer's Assessment

Regional Variations

We have used the term council or trust when referring to the bodies you can seek help and support from. Depending on where you live this will mean:

England and Wales – your local council, local authority or social services

Scotland – your local council, local authority or social work department

Northern Ireland – your Health and Social Services Trust

Carers are often tempted to think that they do not need an assessment when so much is already going on in the life of the person with PSP. But the law says that anyone who is providing – or intending to provide – a substantial amount of care on a regular basis can have a Carer's Assessment.

What is it?

The aim of a Carer's Assessment is to find out more about your needs. It has nothing to do with the person you are caring for – it is about your needs, not theirs.

It is not just about hands-on caring either. If the person with PSP is affected by behavioural changes, for instance, you might have to invest a considerable amount of time ensuring that they are safe. When you prepare for your assessment, consider the impact that caring has on you – such as your own health, relationships and work. And don't forget to mention the things that you can no longer do due to your caring role.

How do I get an assessment?

Everyone in a caring role is entitled to a Carer's Assessment. This will be carried out by the local authority social services department in the area where the person you are caring for lives. If you don't live in the same area as them, this means you will have to apply to their local council or trust for the assessment.

The aim of the assessment should be outcome-based:

- To highlight any more support you might need in your caring role
- To enable you to maintain your own health and wellbeing so that you can balance caring with other work and family commitments.

You can apply for an assessment whether or not you live with the person you are caring for. You can also apply if you are caring full time, or if you are working as well as caring.

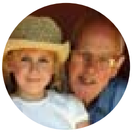
The assessment will look at any help you might need in order to carry out your role as carer, and how the caring role affects you. It will also consider how much caring you can manage, whilst still having time for your other interests and activities away from caring.

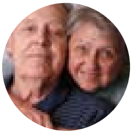
Top Tip

Carers UK publish a good *Carers Assessment Guide*, available by visiting www.carersuk.org to download a copy, or call the CarersLine on 0808 808 7777 to request a copy by post

Be sure to request a further Carer's Assessment when circumstances change

NHS Choices provide an online essential guide to social care. Visit www.nhs.uk/carers or call 0808 802 0202 for more information.





Getting help

Sometimes, when you are in a caring role, it is difficult to admit that you can not do everything. As PSP progresses, you will probably need to find other people to help with caring. Finding the right kind of help is important for your peace of mind as the carer, as well as the person you are caring for.

There is a range of options available – some will depend on your financial situation.

These include:

- Asking friends or family to help out
- Employing someone to help
- Arranging residential respite care so that you can have a break.

Use the support around you - establish a support network

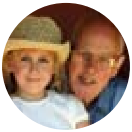
Caring for someone can be physically and emotionally demanding. Sometimes you might feel like you are the only person having to deal with everything caring requires.

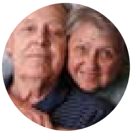
Think about establishing a strong network of people around you - your family, friends and any others who can help if times get tough.

Sometimes, you might feel that you ought to be able to cope with everything life throws at you. There might be times when you feel that your caring role is quite demanding and that seeking help might be a sign that you can not cope. But don't be afraid to admit that you would appreciate some help. It can be hard for us to accept it, but as a carer, it can be vital. Sometimes, family and friends are unsure of what kind of help they can give.

They may be a bit vague, and say things like 'let me know if I can do anything.' In that situation it is good to have some clear role they can help out with, such as asking if they can collect some shopping or pop in one afternoon a week to sit with the person with PSP so that you can go out.

Sometimes, people don't offer their help, thinking you might be offended. It's good to reassure them early on in your role as a carer that support will often be very welcome!





Balancing work and caring

If you are combining working and 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

If you have a job as well as caring for someone with PSP, there is no doubt it can be difficult at times. You may feel that you are juggling all the demands of work and caring and sometimes wonder how you can possibly keep all the balls in the air at once.

You may be tempted to give up work straight away, but it is important to explore all the options first. Many people really enjoy their working life – the challenges, friendships and financial benefits it brings.

Over half of all carers in the UK do some kind of paid work as well. Your needs will vary from someone who is in a full-time caring role. Depending on your personal situation, you may decide to tell your employer about your caring responsibilities. If you are not sure what to do, talk to colleagues and your human resources department about ways your workplace could support you.

Other organisations that can help

Striking the right balance between your role as a carer and looking after your own health can be really challenging. As well as help and support from friends and people close to you, the PSP Association is also here when you need us.

In addition, advice, support and information on all aspects of caring can also be obtained from the following organisations:

Age UK

Provides advices and information for people in later life.
Publications, online support and telephone advice
Telephone: 0800 169 6565
Website: www.ageuk.org.uk

Carers UK

Offers practical information and advice, practical and emotional support.
Telephone: CarersLine 0808 808 7777
Website: www.carersuk.org

Northern Ireland

Telephone: 028 9043 9843
Website: www.carersuk.org/northernireland

Scotland

Telephone: 0808 808 7777
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As PSP progresses, you may also find some other information useful in **Section 4 – *Later in Life.***

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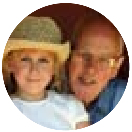

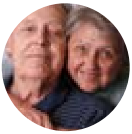

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How to contact us:

Telephone: 0300 0110 122
Email: helpline@pspassociation.org.uk

The PSP Association
Margaret Powell House
415a Midsummer Boulevard
Milton Keynes MK9 3BN

"I can't thank you enough for your time –really valuable information here. Although I have support from lots of health care staff without you I feel I would be on my own, you make all the difference".

Deborah

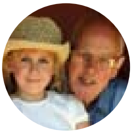
Section 4

Later in life

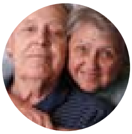
This section includes:

- Respite care
- Continuing healthcare
- End of life decisions
- Legal issues
- Tissue donation
- Making a will
- Leaving a legacy
- Funerals
- When caring ends
- How the PSP Association can help

Progressive Supranuclear Palsy
PSPA



Later in life

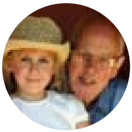


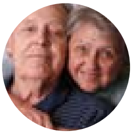
Introduction

This section covers a range of subjects that may be relevant to people with PSP and people close to them as the condition progresses.

Remember not all of this is relevant to everyone and a lot of the information contained here is intended to give you the facts on certain issues, leaving you to make your own personal choices, at a time that's right.

Respite care





Respite care offers you a break from your normal environment and can also give your carer a welcome opportunity to recharge their batteries too. There are many types of respite available.

Brief respite

Brief respite can be useful when your carer needs to go out but does not want to leave you alone. Your local social service department should be able to provide advice on how to access this service.

Friends and family will often be happy to help out for a few hours, and you may find that you enjoy a change of social scene too. Don't be nervous about asking for help from friends rather than struggling on alone.

As the condition progresses, you may sometimes feel that your social life is reduced and getting the opportunity to catch up with old friends in this way can be refreshing as well as practical.

Longer periods

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

Because PSP is quite rare, not every member of staff will have heard of the condition and it is advisable to let them have as much information as possible about how it affects you.

Staff will need to understand the demands of the condition, especially if there are speech, cognitive or falling problems. Try to make an appointment to speak to staff who will be directly involved and provide them with personalised copies of the *All About Me* leaflet at the back of this pack.

If they need further information, give them the contact details for our helpline, information and advisory service.

Another option you might like to consider is to approach a friend or family member to see if they would be able to 'live in' whilst your carer takes a short break.

It is also worth considering nearby hospices for a short stay. You can approach them directly, or by referral from your GP. You may associate the term hospice with end of life, but in fact they can offer a range of specialised services for people with complex conditions, such as PSP, and their families, from a very early stage.

It's a good idea to plan respite breaks into your calendar on a regular basis - this gives both of you something to look forward to and becomes part of the care routine.

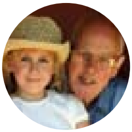
You can find your nearest hospice by contacting Hospice Information:
www.hospiceinformation.info/findahospice.asp and then click on relevant country tab. Or call 0870 903 3903.

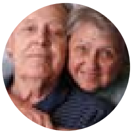
Direct Payments

If you receive help from social services you will be able to apply for Direct Payments. These let you choose and buy the services you need yourself instead of getting them from the local council. They are available in England, Scotland and Northern Ireland. If you live in Wales or Scotland, contact your council directly.

You can only get Direct Payments if you have been assessed by social services as needing care and support services.

For further information search for *Direct Payments* at www.gov.uk or www.nidirect.gov.uk (Northern Ireland).





Continuing healthcare (CHC)

For most people with PSP, assistance and care will be provided by the local social care team. Social care provision is means tested and therefore you may find that you need to make a contribution towards the costs of providing this.

However, should your needs become more complex and health based, you may be entitled to receive CHC funding.

What is it?

CHC is the name given to a package of care that is arranged and solely funded by the NHS for individuals who are not in hospital, but who have complex, ongoing healthcare needs. It is only available for those that meet specific eligibility criteria. Not everyone with a disability or a long-term condition will be eligible, as the assessment is based on the existence of complex needs rather than a specific diagnosis.

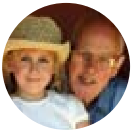
CHC can be provided in any setting, including your own home, a care home or a hospice. If you live in a care home, for example, CHC will cover care home fees, including accommodation, personal costs and healthcare. If you stay in your own home it covers your personal care and healthcare costs and may also cover support for your carer.

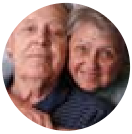
The assessment required to apply for CHC is very detailed, and will require written evidence from key health and social care professionals involved in your care, as well as information from you and your family.

Tips on applying for NHS continuing healthcare

- The health and social care professionals involved in your care should be able to co-ordinate the application process for you. Speak to your GP, social worker, district nurse or community matron to get the ball rolling
- Compile a history of the type of care that you need, and how frequently you need it. This may come in handy if you are refused CHC in the first instance, because you will be able to pinpoint any subsequent changes in your condition that may suggest a further application later
- Keep a brief note of all communication with health and social care providers about your needs. Include the date, time and name of the person you spoke to
- Keep a copy of all correspondence
- If possible try to attend all assessments and hearings in person, or get a family member or friend to go on your behalf.

If you have any queries regarding CHC please speak to our helpline, information and advisory service.





End of life decisions

Planning ahead

For most of us, talking about end of life choices is not easy and can sometimes feel overwhelming. Some people prefer not to think about it all, as it may bring to mind issues about their illness and their future, which they are not yet ready to think about. Others prepare as soon as they can giving everyone a chance to talk and share their feelings. It can give you peace of mind to be prepared emotionally and practically. Planning your future with the people in your life may help you, your family and friends to feel more confident and reassured with what lies ahead. This process is known as advance care planning.

What is advance care planning?

It can be difficult to open a discussion about advance care planning because it involves many end of life choices. Not everyone will want to have such a conversation, and if you choose not to then that is fine.

However, taking part in advance care planning will ensure that your wishes and preferences will be known to others, and will enable those responsible for your care to make decisions on your behalf if you become unable to make decisions for yourself. When you have PSP it is often best to have these discussions as early as possible, before any issues with speech or cognition make it difficult to communicate your preferences.

Advance care planning does not need to be in writing, with the exception being any Advance Decisions to Refuse Treatment. However, it may be handy for you to have a written record of your preferences to be passed on to everyone who needs to know about your wishes. Remember to keep a copy safe, and to review it regularly so that you can make any changes or update it as you wish.

Advance care planning is a discussion between you and those who care for you - your family and friends, doctors, nurses, social workers or care home managers. It is a chance for you to explore your options and express your views regarding your preferences and wishes about your future care. The process of advance care planning ensures that your wishes and preferences will be taken into account if you are unable to make decisions at some point in the future.

Factors affecting decision making

If you are no longer able to make decisions for yourself - whether for some or all of the time - you are said to have lost mental capacity. The Mental Capacity Act 2007 came into force to ensure that every effort is made to include the individual in decision-making, and take into account their wishes, feelings, values and beliefs. The Mental Capacity Act applies to people in England and Wales. For Northern Ireland please refer to the Mental Health (Northern Ireland) Order 1986, and for Scotland please refer to Adults with Incapacity (Scotland) Act 2000.

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.

This is particularly relevant for people living with PSP, where both cognitive and speech problems can eventually make it impossible to make or communicate a decision. 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.

What can be included in an advance care plan?

As part of the plan, you may wish to explore your thoughts, feelings and preferences regarding some of the following issues;

- Preferred place of care
- Advance Decision to Refuse Treatment (ADRT)
- Lasting Power of Attorney (LPA)
- Wills
- Funeral arrangements
- Tissue donation

You can include anything in your advance care plan that is important to you. Nothing is too trivial, it is your plan to tailor as you wish, so you can add in anything that reflects your beliefs and values, and how you like things to be done.

It is important to note that advance care planning is an entirely voluntary process. You do not have to do it, and you should never feel under pressure to do so. However, if you do decide to take part, the discussions that you have around the topics mentioned above may help your family and friends to feel more confident about making decisions on your behalf in the future, whilst giving you peace of mind that your wishes will always be considered.

Your views may change over time so it is useful to have regular discussions and update the relevant documents if necessary. Please note that any decisions you make can be updated and changed whenever you want and your advance care plan will only come into action if you are no longer able to make your own decisions.

Preferred place of care

One of the key decisions of advance care planning is where you would prefer to be at the end of your life. Often the choice of where you die depends on what you want, what help you have from family and friends and what services are available in the area you live.

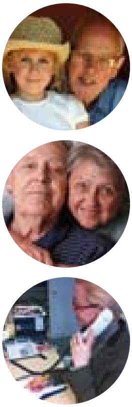
There are four main places where people with PSP may wish to be:

- **At home** – Many people will want to stay at home in familiar surroundings with their close family around them. If this is your choice, family carers will require extra support during this time from the GP and health professionals. If you are linked into the community palliative care team they can also offer advice and support
- **In hospital** – If you have been in and out of hospital over the last few months, you may want to go back to your usual hospital ward when you need full-time nursing care. However, this may be difficult to organise if the ward is very busy. Many people die in hospital, but a busy ward may not be the most peaceful place. Often you will need to fit into the ward routine, rather than being looked after in the way that you would like
- **In a nursing home/care home** – For many people, a move to a nursing or care home is often triggered by

some kind of crisis – perhaps when there is a breakdown in the support you receive at home. This can happen for a variety of reasons, but there is help available that may enable you to stay at home if you wish, so you should never feel pressured into thinking that you have to move into a nursing/care home. Think about the reasons why you may be considering a move to a nursing home in the future, and if it feels like something you may really want then talk things through with your family and friends. You may also find it helpful to talk things through with your doctor or social worker. Remember, the final decision is yours, although if there are issues relating to your safety then this could be subject to change

- **In a hospice -** Hospices specialise in the care of people who are dying. Hospices are very different from hospitals. They are quieter and tailor their care to suit each person, and for this reason you may wish to explore the possibility of spending time there during the end stages of your illness. It is important to note that hospice services are not necessarily focused simply on the end stages of an illness. The care provided by a hospice (often referred to as palliative care) is a holistic or whole person approach that not only takes care of the physical needs of the individual but also looks after emotional, spiritual and social needs. They aim to support people diagnosed with a life limiting illness, and improve quality of life through expert management and treatment of symptoms, as well as providing support to family and friends. Obtaining an early referral to the hospice team (even at diagnosis) is particularly beneficial to people living with PSP because the earlier this relationship begins, the more support you can receive.

Legal issues



Advance Decision to Refuse Treatment (ADRT)

You may want to discuss specific life sustaining treatments that you do not wish to have. An Advance Decision to Refuse Treatment (ADRT) is a choice you can make in advance to refuse specific treatments in certain circumstances in the future. In England and Wales these were formally known as Living Wills. In Scotland it is known as Advance Directives. There is currently no legislation in Northern Ireland covering an ADRT.

Before making an ADRT, you should discuss your wishes with your doctor or another health professional involved in your care to ensure you are clear regarding which treatments you wish to decline. Any decisions you make need to be communicated to your family and your care team. An ADRT can be reviewed and amended at any time should your wishes change.

An ADRT is legally binding and only becomes valid once you lose the ability to make or communicate those decisions.

There is no set format for an ADRT but it must be in writing. You can ask a health or social care professional, such as your GP or hospital team who are already involved in your care for an ADRT form.

If you have decided to refuse specific treatments in the future you must be sure that the people involved in your care know this. Ask your nurse or doctor to help you do this.

For more information and to view template ADRT forms (England and Wales) visit www.compassionindying.org.uk
For more information about making Advance Directives (Scotland) visit www.compassionindying.org.uk/scotland

Asking someone to speak for you

It is possible to nominate one person or more (perhaps close friends or family members) who can be asked to provide information about your preferences, wishes, feelings and values. In this scenario, if you were unable to make a decision for yourself at some point in the future, then professionals in charge of your care would be able to consult with your named person. Whilst the named person cannot actually make a decision on your behalf, they can provide the professionals with invaluable information that can help them to make decisions for you and act in your best interests. If you decide that you would like to nominate someone to speak for you then it is a good idea to have their name recorded in your advance care planning documentation so that everybody is aware.

Naming someone to speak for you in this way is not the same as legally appointing someone to make decisions for you as your Power of Attorney. Please see below.

Power of Attorney

Appointing a Power of Attorney allows you to choose someone you trust to take actions and make decisions on your behalf. This varies across England, Wales, Scotland and Northern Ireland.

England and Wales – Lasting Power of Attorney

In England and Wales a Lasting Power of Attorney (LPA) allows you to choose someone you trust to take actions and make decisions on your behalf if you are unable to communicate your wishes. There are two types of LPA:

- Property and financial affairs LPA – for decisions including paying bills, collecting benefits and issues relating to property. It is important to note that if you decide to allow it, your LPA for Property and Finance can act on your behalf even when you have capacity
- Health and welfare LPA – for decisions including where to live, day-to-day care and medical treatment. The LPA can ***only*** be used if you are unable to make a particular health or welfare decision yourself.

You may appoint different attorneys for each LPA if you wish, and you can limit decisions that they may or may not make on your behalf. The attorney has a legal duty to act in your best interests at all times, considering your preferences and involving you as much as possible in the decision making process.

In England and Wales you can register a Lasting Power of Attorney with the Office of the Public Guardian. Please note that there is a charge for this.

For more information search for *Lasting Power of Attorney* at www.gov.uk

Northern Ireland - Enduring Power of Attorney

In Northern Ireland an Enduring Power of Attorney (EPA) is registered through the Office of Care and Protection. An EPA only enables decisions on your behalf for property and finance, not healthcare needs.

For further information search for *Enduring Power of Attorney* at www.courstni.gov.uk

Scotland – Continuing Power of Attorney and Welfare Power of Attorney

In Scotland a Continuing Power of Attorney (CPA) can be registered for financial affairs, and a Welfare Power of Attorney (WPA) for healthcare needs. You can also make a Power of Attorney which deals with both financial and healthcare needs. These have to registered through the Office of the Public Guardian (Scotland)

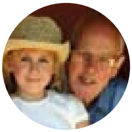
For further information search for *Power of Attorney* at www.publicguardian-scotland.gov.uk

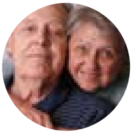
Useful contacts

Age UK LifeBook - a free booklet to document important and useful information, from who insures your car to where you put your TV Licence. Visit www.ageuk.org and search for LifeBook, or telephone 0800 169 6565.

Advance Decision to Refuse Treatment - website for professionals which contains a section for patients.
Website: www.adrt.nhs.uk

Dying Matters - leaflets and information on end of life care and planning ahead.
Website: www.dyingmatters.org





Tissue donation

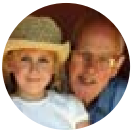
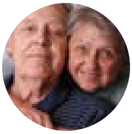
The topic of tissue donation is a sensitive and a very personal one. Tissue donation helps towards a better understanding of PSP, and the chance to further medical research provides strong motivation for people to donate. Anyone can become a potential donor – including people without PSP. This enables researchers to compare what happens in a brain affected by PSP with one not affected by PSP. Therefore anyone can make a valuable contribution to research into the treatment and eventual cure of PSP by donating their brain after death. If after reading through this information, you decide you would like to donate your brain tissue for use in research please ensure that your wishes are known to your family and everyone who is involved in your care. It is important to plan ahead, to ensure your wishes are met.

The PSP Association fund the Sara Koe PSP Research Centre (SKRC) which is based at the Institute of Neurology in London. The research team have many years of experience and are available to discuss the importance of brain donation with people living with PSP/CBD and their relatives, so that consent can be given in an informed way.

The first step towards donating is to gather as much information as possible so any decision you make is based on expert advice and knowledge. You can do this by contacting the SKRC who will answer any questions you may have and provide you with the forms that you will need to complete. It is important to talk to family members so that they understand your wishes. If you make a decision to donate your brain, you are free to change your mind, should you wish to do so, at any time.

When you have registered with the SKRC there is nothing else you need do other than to keep all the paperwork in a safe place with the telephone number of the centre. Brain donation needs to take place within 48 hours after death. It is therefore important that your family contact the centre as soon as possible. The centre will co-ordinate with the funeral director, GP and the hospital as necessary. They will then liaise with the funeral director to make sure the body is safely returned.

If you would like more information on Brain Donation please contact Lynn Haddon, Administrator for The SKRC.
Telephone: 020 7837 8370
Email: l.haddon@ucl.ac.uk

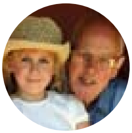



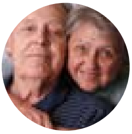

Making a will

A will is a legally binding document that sets out what will happen to your money and possessions when you die. If you die without making a will (known as dying intestate) your money will be used to pay off your debts and then shared amongst your family.

You can make your own will - some stationers provide legal packs - or you can instruct a solicitor to make one for you. It is usually best to get advice from a solicitor except in very simple circumstances.

Leaving a legacy



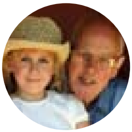


How a legacy to the PSP Association will make a difference

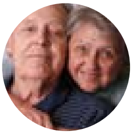
Whatever the value of a legacy it will help the PSP Association to support people living with this devastating disease and to provide a secure financial base to further the Association's work to find a disease-modifying treatment and an eventual cure. We need additional funding to:

- Recruit more PSP specialist care advisers
- Expand the network of local 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 would like to discuss any aspect of leaving a legacy to the PSP Association or would like further information please telephone: 01327 356130.



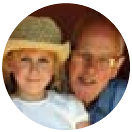
Funerals

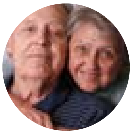


Many people die without making any plans for their funeral. For family or close friends who are left behind, arranging a funeral can be stressful if they do not know exactly what type of funeral service you want or how you would like it carried out.

If you explore what you want with your family or friends, it will provide them with the confidence to carry out your wishes.

Many people worry about whether a funeral will be affordable for their loved ones. A pre-paid funeral plan may be possible or the person arranging the funeral maybe entitled to a benefit payment to help with the cost.
For further information search for *Funeral Payments* at www.gov.uk





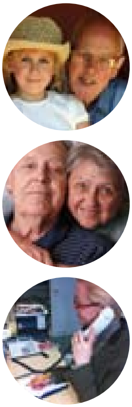
When caring ends

Looking after someone with a progressive illness can become a large part of the carer's life and the role of the carer will change as that journey goes on.

Losing someone close to you is a significant change in anyone's life and if they have been caring for that person as well, the loss can seem even greater. People cope with bereavement in many different ways. Just as dealing with PSP is uniquely personal, so is the way that people deal with the end of life.

Remember that everyone's reaction to the loss of someone is different. There is no right or wrong way to deal with grief. There is no prescriptive 'time' that grieving lasts, and sometimes grieving does not happen immediately after a death.

It's always a good idea to talk to your GP as soon as you can. If you feel it would help, they are able to refer you to a range of services that can help support you as you adjust to life after caring. You may find it helpful to talk to a counsellor or bereavement support group.



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

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

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

The PSP Association
Margaret Powell House
415a Midsummer Boulevard
Milton Keynes MK9 3BN

"It is so nice to talk to someone who is listening to me."

Beryl

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Margaret Powell House
415a Midsummer Boulevard
Milton Keynes MK9 3BN
Telephone 01327 322410
Email psp@pspassociation.org.uk
Website: www.pspassociation.org.uk

Helpline: 0300 0110 122
Email: helpline@pspassociation.org.uk

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