



# A PROFESSIONAL'S GUIDE TO PROGRESSIVE SUPRANUCLEAR PALSY



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FINDING A CURE **STARTS  
HERE**

**This summary guide has been developed to support all professionals working with people affected by Progressive Supranuclear Palsy (PSP).**

**It includes an overview of standards of care and best practice for all those working with, providing services for and supporting people living with PSP.**

**In depth information is available through our online interactive resource which can be accessed via desktop or tablet.**

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**This guide has been developed following a commitment to review and update the 'Pathway of Care for PSP. A guide for Health and Social Care Professionals' which was first published in 2012. The guide follows the same format as the Professionals Guide to Corticobasal Degeneration and is complemented by an interactive web-based resource providing more in depth information.**

**Thanks to UCB Pharma Ltd who kindly supported this guide through an unrestricted grant.**

**Andrew Symons, CEO**

## INTRODUCTION

PSPA's vision is to make life better for those living with PSP, their carers and family members.

This guide has been written following discussions with people living with PSP and the professionals supporting them. These discussions identified that clear information about rare conditions is needed by:

- Health and Social Care Professionals who support people with a diagnosis of PSP
- Those with a diagnosis of PSP
- Carers who help people with a diagnosis of PSP
- Families and friends of people with a diagnosis of PSP.

The guide is written for professionals. It may also be a helpful resource for people living with PSP, enabling them to have informed conversations with the health and social care professionals they will need to meet. To further support these conversations, a separate pocket guide has been developed that is written specifically for a lay audience, highlighting the type of care they should expect.

### THE GUIDE PROVIDES:

- An overview of the standards of care that people with PSP, their carers and family members should expect
- Links to further information and evidence
- An on-line interactive guide and up-to-date framework that can be viewed on a desktop or tablet.

This flexible approach means that everyone can access the best standards of care and good practice to inform treatments as well as support those with more limited knowledge. It provides clear, precise, evidence based and up-to-date information in one place, encouraging consistency of care across all geographic areas.

PSPA would like to thank all those involved in the development of this guide:

People with PSP, their carers and family members

Health and Social Care Professionals

PSPA staff and volunteers

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## WHAT IS PSP?

PSP is a rare neurodegenerative disease. It is the most common parkinsonian disorder after Parkinson's disease (PD) and is often misdiagnosed as PD due to similar symptoms in the early stages.

### KEY POINTS ABOUT PSP:

- PSP is sometimes referred to Steele-Richardson-Olszewski syndrome. The disease presents as a continual deterioration (progressive) which damages nerve cell clusters in the brain that control eye movement (supranuclear) as well as causing weakness (palsy)
- 5 people per 100,000 in the UK have PSP (a similar number to MND and less common than PD)
- New evidence indicates approximately 50% of people affected are initially misdiagnosed with similar neurodegenerative conditions meaning numbers living with the condition could be much higher
- Typical age of onset is 60-65, but people may be affected from their 40's
- Life expectancy is very variable. Typically, it is in the range of 5-7 years following symptom onset, however individual health factors mean it can be shorter or longer. Good multidisciplinary care may improve both the quality and length of life for those with PSP
- It is caused by the build-up of a protein called tau in certain areas of the brain and forms into clumps (neurofibrillary tangles), which are believed to damage nerve cells, resulting in them dying back earlier than normal
- Visual disturbances which may be difficulty looking up and down, focussing, double or tunnel vision and a dislike of bright lights

- Psychological problems in PSP can include changes in mood and behaviour, including depression, apathy and difficulty making decisions (PSP can affect mental capacity)
- No two people present in the same way and an individualised patient-centred approach should be taken.

### THE IMPACT ON THE PERSON CAN INCLUDE:

- Difficulties with activities of daily living such as cutting up food, doing buttons and dressing
- Mobility problems such as unsteadiness, balance problems and falls (often backwards). This progressively deteriorates and many individuals become immobile
- Visual problems may contribute to falls
- Communication difficulties such as reduced speech, quiet voice and palilalia (repetition of words)
- Cognitive changes and apathy may lead to some withdrawal and difficulty engaging in social interaction
- Progressive changes resulting in increasing levels of care which often fall on family members, particularly the spouse. These changes to independence can be difficult to adjust to or accept.

## DIFFERENCE BETWEEN PSP AND

## PARKINSON'S DISEASE

FEATURE	PSP	PARKINSON'S DISEASE
Falls	Often backwards	Falls forward Early falls are rare
Vision	Difficulty with up and down gaze	Eyes move in a slow jerky movement
Posture	Axial rigidity, erect posture, tendency to fall often backwards	Tendency to bend forward
Speech and Swallowing	Late onset	Early onset
Tremor	Rare	Common
Response to levodopa	Minimal/brief response	Good response

## STANDARDS OF CARE

This is a summary of the standards of care, an extended version with quality statements and suggested ways of measuring a service practice can be found on our website <https://hscpguide.com>

### BEFORE DIAGNOSIS:

- Recognition of 'Red Flags' that may point to PSP rather than Parkinson's disease, stroke, dementia or depression, including: a progressive symmetrical axial rigidity, abnormal eye movements such as loss of downward gaze and involuntary eyelid spasms (blepharospasm), lack of tremor
- Speedy referral to a neurologist is recommended if PSP is suspected or there is doubt about the diagnosis. Early referral and accurate diagnosis ensures early access to information, support and services.

### AT DIAGNOSIS:

- The diagnosis should be made and given by a neurologist with knowledge and experience of PSP
- Wherever possible, a supporting family member or friend should be present when the diagnosis is given
- Relevant written information should be offered including access to supporting organisations
- Early follow up appointments should be offered
- Comprehensive information should be sent to the GP and the relevant key worker
- A care plan with appropriate referrals to the multidisciplinary team should be made.

## DURING THE PROGRESSION OF THE CONDITION

### COORDINATION OF CARE BY A MULTIDISCIPLINARY TEAM

- A named key worker/or point of contact
- Good communication and coordination across health and social care professionals, including hospital, primary care, community and palliative care teams is essential
- Holistic person-centred approach to care planning
- Regular reviews of care and medication, without discharge, to maintain continuity throughout disease progression
- Early referral to specialist palliative care team should be offered to assist with symptom management and advance care planning
- Patients and carers have an up to date list of their care team including names, addresses and phone numbers of their doctors, clinical nurse specialists, therapists, social workers and community teams.

### ACCESS TO INFORMATION

- Patients and carers should be provided with details to be able to access medical care, information and support between outpatient appointments
- Regular signposting to information in an appropriate format as the disease progresses
- Early access to information for the person with PSP as well as carers and family members.

### EDUCATION OF PROFESSIONALS

- Information for GP's and other health professionals
- Education for social service representatives
- Education for paid domiciliary care and residential care staff.

### SUPPORT FOR CARERS

- Information and support on the condition and how to provide care
- Information and access to services in the carer's own right including a Carers Assessment can be found on our website [www.pspassociation.org.uk](http://www.pspassociation.org.uk)
- Information and support for respite from the caring role.

### ACCESS TO EQUIPMENT AND MEDICATION

- Anticipatory prescribing of appropriate equipment and adaptations to maximise independence
- Anticipatory prescribing of medication for symptom control to minimise hospital admissions (avoidance of dopamine – 2 antagonists such as metoclopramide).

### ACCESS TO INFORMATION ABOUT RESEARCH OPPORTUNITIES

- Research participation can be a very positive experience and motivation for many individuals and their families.

## ADVANCED STAGES AND END OF LIFE CARE

- Anticipation and recognition of advancing disease and end of life to ensure appropriate preparations are in place
- Early conversations regarding advance care planning, including ADRT, wishes about care, including place of care and death
- Registration on GP palliative care register and available urgent care plan systems e.g. Coordinate My Care (CMC)
- Early access to the palliative care team
- Close monitoring of symptoms during advanced stages
- Access to appropriate support from staff trained in end of life care
- Access to emotional and practical support for carers and family members
- Access to equipment, such as hoists, beds or syringe drivers to enable care at home if this is wished by the person and family
- Provision of extra care so that the family are able to reduce their caring responsibilities and spend time with the person.

## SNAPSHOT OF SYMPTOMS

The following section provides an overview of symptoms the person with PSP may experience. They are not in order of importance, as each individual presents differently. Impairment in some areas may be quite advanced before a definitive diagnosis has been given, and impairment in another area might never happen. Early conversations regarding planning ahead may be extremely important in order to consider the wishes of the person with PSP, particularly if there are signs of communication and cognitive change. It is important for health and social care professionals to:

- Prioritise the needs of people with PSP and family carers
- Focus on quality of life; there are many treatment options but no cure
- Ensure multidisciplinary care and add to the support system for the family as needs change
- Plan for the future.

## MOVEMENT AND BALANCE

A person with PSP may first present with a movement disorder which may have an impact on activities of daily living. The individual may experience minor difficulties with complex and fine motor tasks such as writing, tying shoelaces and fastening buttons. There may be some slowness of movement and balance is often unsteady resulting in falls which are often backwards. As the disease progresses postural reactions may become increasingly impaired with a tendency toward risky movement. This, with increasing muscle rigidity, may lead to immobility and very limited movement of the extremities. The focus of support should be on independence, prevention and safety.

- Early referral to physiotherapist and occupational therapist to maximise independence. Access to physiotherapy to maximise mobility and movement as difficulties arise is essential
- Consider referral to a Falls Prevention Clinic if assessment indicates specific risk. The ability to retain advice given should be reviewed as this impacts on the management of impulsive behaviour
- Assess fracture risk, bone protection and osteoporosis treatments
- Later in the disease, impaired postural reactions, muscle rigidity and significant reduction in mobility will require anticipatory prescribing of appropriate mobility aids. Visual impairment should be considered when prescribing aids
- The person should not be discharged from the MDT, or individual practitioners' caseloads and there should be close and ongoing liaison with social services, particularly if home adaptations are needed. Automatic reviews should take place every six months as a minimum
- Family carers and paid care workers may need advice regarding movement and handling. Increased social care support may be needed where individuals exhibit impulsive behaviour
- Positioning will be important to minimise risk of contractures and pressure areas developing
- Stiffness/contractures or dystonia can be problematic and lead to pain in sitting and difficulty dressing. These may respond to regular splinting or botulinum toxin injections in association with intensive physiotherapy. Sometimes anti-stiffness medication may help. Parkinsonism symptoms may respond to dopaminergic medications or other drugs, under specialist supervision. Apraxia does not respond to medication.

## COMMUNICATION AND SPEECH

The person with PSP may experience speech problems at an early stage in the disease. This may include loss of fluency and distorted speech. In addition, cognitive change and visual difficulties can also affect communication and social interaction. As the disease progresses communication may be extremely challenging as speech becomes very erratic, visual changes affect eye contact, cognitive change impacts social interaction and changes to dexterity may affect the use of communication aids.

- Prompt referral to a speech and language therapist is important and the individual should not be discharged from the caseload following initial assessment. Episodic care should be provided depending on the needs of the individual. Discussion regarding care plan, goals and (if necessary) re-referral back into the service which undertakes a long-term caseload review should be documented
- Any communications aid assessment needs to consider the visual, motor and cognitive problems as well as low-tech back up
- Anticipatory prescribing of equipment and referral to specialist Augmentative and Alternative Communication (ACC) centres where indicated, with consideration of voice banking
- Early discussions about planning ahead are essential to ensure the individuals advance care choices are documented as speech difficulties may prevent these being communicated
- Family carers will need support in adapting to significant changes in communication ability towards the end stages.

## COGNITIVE BEHAVIOUR, INCLUDING EMOTIONAL CHANGE

Cognitive changes can arise as a side effect of medication, directly as a symptom of the condition and/or as a reaction to aspects of the condition. They can occur early on in the condition and are likely to increase as the condition progresses with a high proportion of people experiencing a type of dementia. These changes can be particularly hard for family and carers to come to terms with and manage. Patients can become emotionally labile and exhibit challenging behaviours. They may be impulsive or irritable at times and have a lack of empathy. They may have difficulties with executive function and at times be disorientated. Some may experience depression and/or anxiety. However, others with PSP may retain normal or near normal cognitive function and insight.

- Consider referral to a neuropsychologist or memory/cognitive clinic
- Consider support needs of family carers including the provision of information and access to psychological support
- Appropriate assessment is needed to avoid misinterpreting communication difficulties as cognitive decline
- Early advance care planning is of particular importance where there are changes in cognition, particularly in conjunction with communication decline and should be regularly reviewed. Consider early referral to palliative care to support this process
- Ensure all involved in care are aware of cognitive change and are able to help the person appropriately
- Be aware of the higher risk of cognitive side effects from medication including medication used to treat other problems like bladder and sleep symptoms
- Psychosis is rare in PSP. It is most commonly caused by infection (delirium) or medication (e.g. opiates, amantadine or dopamine agonists).

## SWALLOWING AND NUTRITION

Over 80% of those diagnosed with PSP will experience difficulty swallowing in the moderate to severe impairment stages of the disease. It should be carefully monitored throughout the progression of the disease as recurrent respiratory infections are frequent and should be treated promptly to prevent hospital admission or the risk of premature respiratory-related death.

- Prompt referral to a speech and language therapist for advice on swallowing strategies, alongside referral to a dietitian to ensure nutrition and hydration needs are met, is essential. The person should not be discharged once initial assessment has taken place and regular reviews are essential
- Supplementary nutrition for calorie and vitamin intake may be required
- The difficulty in managing saliva can have a distressing psychosocial impact. Coping strategies to manage saliva, including use of medication to manage thin as well as thick tenacious secretions should be considered. Oral suctioning may be helpful to clear oral secretions
- Any decrease in arm function will result in the need for family carers to support feeding and advice on eating in social situations may be useful
- Meal times may take longer, with the need for paid carers to provide additional support
- For those with swallowing problems, discuss gastrostomy feeding as an alternative method of feeding with the person with PSP and family carers. Appropriate information about improving quality of life and preventing complications of weight loss should be provided. Where indicated discussions around gastrostomy (PEG or RIG) feeding should be held early in the disease process. It may be appropriate to discuss 'risk feeding' as an alternative to, or in

conjunction with, gastrostomy feeding. Attitudes change during the course of the illness

- Advance care planning is important with the person with PSP to ensure their preferences are documented with regard to interventions, ceilings of treatment and preferred place of care
- Frequent respiratory infection, aspiration pneumonia and/or breathlessness may be indicative of a move toward the end of life and early referral to specialist palliative care support should take place.

## BLADDER AND BOWEL

Many people with PSP may experience problems with their bladder and bowel. Urinary frequency and urgency can be made worse by mobility problems. Constipation is a common symptom and is often the side effect of medication and poor mobility. As the disease progresses functional incontinence may occur, with urinary and faecal incontinence likely in later stages.

- Advice from a dietitian on diet and fluid intake
- Advice on regular bowel care from community nursing team and/or continence nurse is important
- Timely and appropriate access to continence products
- Medication reviews
- For individuals with cognitive impairment, catheterisation should be avoided if possible, however may be necessary in the late stages of the disease.

## FATIGUE AND SLEEP

The person with PSP may experience problems with fatigue and later in the disease with their body clock, resulting in difficulty getting to and staying asleep. As the condition progresses pain, bladder and bowel problems, movement difficulties, communication, anxiety and medication side-effects can all impact on an individual's sleep.

- Refer to occupational therapist for advice on fatigue management strategies
- Consider sleep hygiene measures to aid falling/staying asleep. Bell call systems at night may reduce anxiety
- Hypnotic medication may help the person with PSP but needs specialist input to balance cognitive and motor impairments against sleep deficits. Treating pain, mood changes and bladder function assiduously may improve sleep
- The needs of the family carer must be considered and may include respite care (at home or in care home facility) and medication to aid their sleep in the short term.

## VISION AND OTHER SENSORY CHANGES

Some form of visual disturbance may be experienced by people with PSP and may be a pre-diagnosis symptom. Most people develop a blurring of vision as the disease progresses and develop a vertical gaze palsy (difficulty looking up and/or down) which can contribute to the risk of falls and difficulties with activities of daily living.

- Consider adaptations to the person's environment to reduce the risk of slips and trips
- Communication may be affected if eye contact is impaired
- Consideration of medication to support good eye hygiene should be a part of assessments
- The visual impairment is typically from the failure of the brain to make sense of the information coming in from the eyes. However, treating eye problems like cataracts, glaucoma and using glasses (such as prism glasses) should continue as for any other person to help the brain get the best input possible from the eyes.

## PAIN AND SENSATION

Pain may be a result of PSP itself, or from comorbidities like falls. Sensory changes may make it harder to locate pain in the body. Communication difficulties may make understanding the extent of pain difficult, meaning managing it appropriately may be challenging. Pain may be an increasing symptom towards end of life and a holistic assessment by the GP, palliative care team or neurologist to provide appropriate treatment and medication will be necessary.

- Assessment of pain using non-verbal cues and involving family carers
- Consider using specific pain assessment for non-verbal patients e.g. PAINAD/DisDat
- Referral to a specialist with expertise in movement disorder/pain
- Referral to specialist palliative care advice for severe or complex symptoms
- Contractions and dystonia can be painful and may respond to drug or botulinum toxin and physiotherapy treatment, rather than analgesics.

## PLANNING AHEAD

A person with PSP and their family should be encouraged to discuss planning ahead, particularly if there are early signs of cognitive change. This process can begin early but should continue throughout the disease progression. It will ensure that the person has informed choices and can document their wishes and consider important decisions such as setting up a Lasting Power of Attorney. Many people with PSP have mental capacity to make decisions although extra time and simple language may be required.

- Discussion about advance care planning can begin early but is likely to need ongoing dialogue as people understand and adjust to their PSP. People's views can change during their illness and it is often helpful to review major decisions with the affected person
- Any advance care plans should be checked, readily available and be known to everyone involved in the person's care; family, paid carers, MDT, GP and community services. They also need to be shared with out of hours services where possible using urgent care plan systems where available e.g. CMC
- Talking about ADRT's is important and these signed documents are legally binding (if valid and applicable)
- Those with PSP may also wish to talk about the future including the decision 'do not attempt cardiopulmonary resuscitation' (DNACPR). This should be documented and agreed. In some areas of the UK the DNACPR has been replaced by the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)
- Many people may wish to agree a Lasting Power of Attorney, make a will, make arrangements for their family in the future and make plans for their funeral
- Early referral and close communication with the palliative care team will help to support early recognition of the end of life phase and any changes in emphasis on care needs and symptom management

- Professionals may be involved in very difficult conversations and asked about suicide and assisted suicide. Information about the legal implications of this can be found on <https://www.dignityindying.org.uk/>

## RESEARCH

Many people with PSP like to be involved in research programmes. Research can be both interesting and empowering for people with PSP and their families.

- Research studies into PSP are taking place across the UK, some of which are supported by PSPA
- People are able to register their interest to take part in research studies through the PSPA website <https://pspassociation.org.uk/research/take-part-in-research/>
- They may also wish to donate their brain to research and information about PSP brain banks can be found on our website <https://pspassociation.org.uk/research/take-part-in-research/>

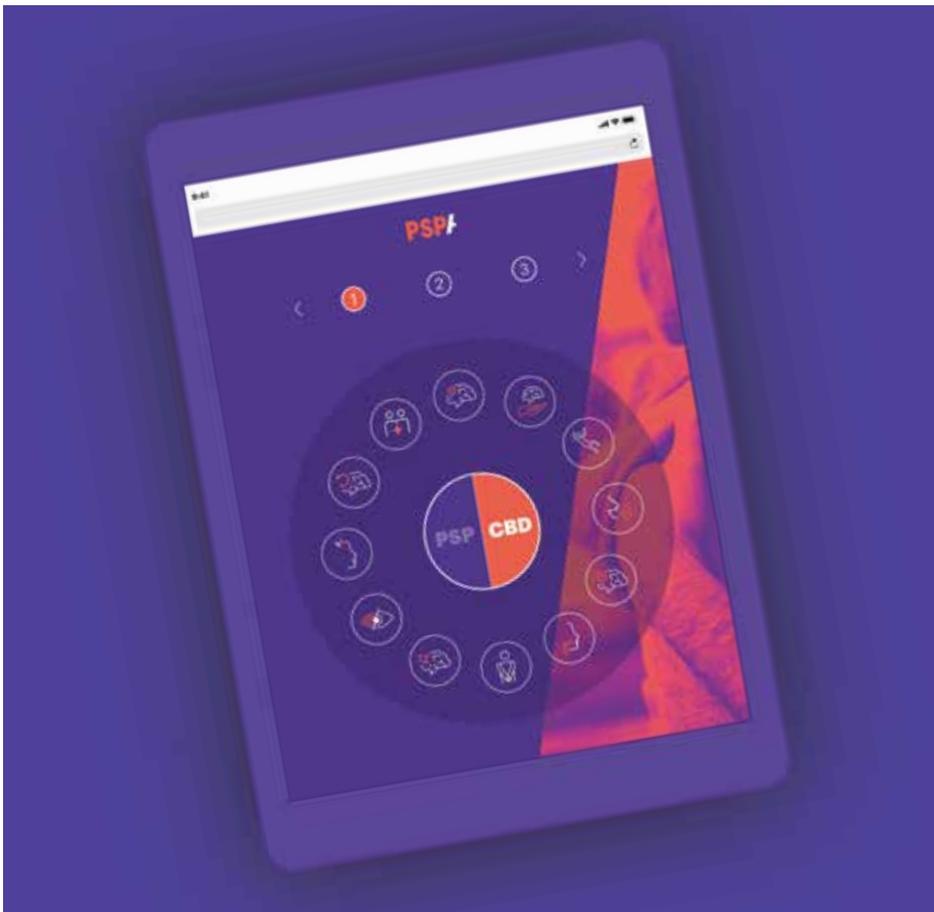
## FAMILY AND CARER RELATIONS

The diagnosis of PSP can have a significant impact on family and carer relations. Changes in mobility, communication, cognition and behaviour all result in increasing demands on family carer time.

- Ensure the GP is aware of the diagnosis and can help the family carer to stay healthy
- Provide information on counselling services
- Provide relevant information on Carer's Assessment, access to benefits and signpost to support networks such as PSPA, Age UK, Carers UK.

## PROFESSIONALS GUIDE TO PSP

### INTERACTIVE RESOURCE



To provide health and social care professionals with more in-depth information, an interactive resource can be found on the PSPA website for use on tablets or desktops PC's.

<https://hscpguide.com/>

The resource gives professionals access to evidence supporting best care at different stages during the disease progression and the ability to build their own personalised guide based on the specific information they may need.

## GLOSSARY OF TERMS

<b>AAC</b>	Augmentative and alternative communication (AAC) is an umbrella term that encompasses the communication methods used to supplement or replace speech or writing for those with impairments in the production or comprehension of spoken or written language.
<b>Advance care plan</b>	Advance care planning is a process that enables individuals to make plans about their future health care. Advance care plans provide direction to healthcare professionals when a person is not able to make and/or communicate their own healthcare choices.
<b>ADRT</b>	An advance decision (sometimes known as an advance decision to refuse treatment, or a living will) is a decision you can make now to refuse a specific type of treatment at some time in the future.
<b>Akinetic rigidity</b>	A type of movement disorder. The major features are bradykinesia (small, slow movements), rigidity and tremor.
<b>Alien limb phenomenon</b>	Refers to involuntary motor activity of a limb in conjunction with the feeling of estrangement from that limb.
<b>Anticipatory prescribing</b>	The prescription of medication or equipment in anticipation of expected changes in symptoms. This would include early prescription for property adaptations to accommodate equipment/aids needed to address changes in mobility (wheelchairs, ramps, hoists etc).
<b>Aphasia</b>	Inability (or impaired ability) to understand or produce speech
<b>Apraxia</b>	Difficulty with the motor planning to perform tasks or movements when asked, provided that the request or command is understood, and the individual is willing to perform the task
<b>Assisted suicide</b>	The act of deliberately assisting or encouraging another person to kill themselves. This is illegal in the UK.
<b>Body clock</b>	The body's natural need to sleep, eat, etc. at particular times of the day.
<b>Botulinum toxin</b>	Also known as BOTOX is used to treat neuromuscular disorders that produce involuntary muscle contractions or spasm. The goal of the therapy is to reduce muscle spasm and pain.
<b>Brain bank</b>	Brain banks store post-mortem brain and central nervous system tissue donated by the public for diagnosis and research into disorders. Advances in understanding genetics and many of the molecules that define brain function mean that more and more research questions can be answered from human brain tissue.
<b>Care plan</b>	Defines the care and support an individual will need and who provides it. It should be documented and regularly reviewed by the care and support team in conversation with the person and their family carers.

<b>Carers Assessment</b>	An assessment of the support a carer (anyone over 18) may be given to help them care for their relative. The assessment is free, however support provided may require a financial assessment (means tested).
<b>Carers Plan</b>	Defines the care and support a carer (non-paid family member) may need to help them care for a person.
<b>Cognition</b>	The mental action or process of acquiring knowledge and understanding through thought, experience, and the senses.
<b>Communication aid</b>	Anything that helps an individual communicate more effectively with those around them. This could range from a simple letter board to a more sophisticated piece of electronic equipment.
<b>Comorbidity</b>	The existence of one or more disorders or diseases at the same time.
<b>CBD</b>	Corticobasal degeneration is a rare condition that can cause gradually worsening problems with movement, speech, memory and swallowing. CBD is caused by increasing numbers of brain cells becoming damaged or dying over time.
<b>CBS</b>	As there is no diagnostic test for CBD, Corticobasal syndrome may be the term used initially whilst other possible CBD mimics such as Alzheimer's and frontotemporal dementia are ruled out.
<b>DisDat</b>	Disability Distress Assessment tool. Intended to help identify distress cues in people who, because of cognitive impairment or physical illness, have severely limited communication.
<b>DNACPR</b>	Do Not Attempt Cardiopulmonary Resuscitation. A DNACPR order refers only to resuscitation if the heart and breathing stops. It does not apply to or alter any other medical treatment or nursing care. A patient with a DNACPR order in their notes will still receive all of the other treatments that they might need while they are in hospital.
<b>Dysphagia</b>	Difficulty swallowing.
<b>Dystonia</b>	Involuntary muscle contractions that cause slow repetitive movements or abnormal postures.
<b>Functional incontinence</b>	The person is aware of the need to go to the toilet, but is unable to do so due to physical or mental difficulties.
<b>Gastrostomy</b>	A surgical procedure, creating an opening from the abdominal wall and inserting a feeding tube (gastrostomy tube).
<b>Holistic assessment</b>	Considers the physical, psychological, social and spiritual needs of a person. It should be a discussion between health care professionals and the individual and their family.
<b>Keyworker</b>	A single point of contact for an individual, usually a member of the multidisciplinary team.
<b>Legal/Lasting power of attorney</b>	A legal document where someone (while they still have mental capacity) nominates a trusted friend or relative to look after their affairs if they lost capacity in future.

<b>Mental capacity</b>	The ability to make or communicate specific decisions at the time they need to be made. To have mental capacity the person must understand the decision they need to make, why they need to make it, and the likely outcome of their decision.
<b>Multidisciplinary care</b>	A multidisciplinary team (MDT) is a group of health care workers who are members of different disciplines (e.g. doctors, nurses, therapists, social workers, etc.), each providing specific services to the patient. The activities of the team are brought together using a care plan.
<b>Myoclonus</b>	Quick, involuntary muscle jerks.
<b>PAINAD</b>	Pain assessment tool for use in advanced dementia.
<b>Palliative care</b>	The active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.
<b>Parkinsonism</b>	Parkinsonism is a term that covers a range of conditions that have similar symptoms to Parkinson's.
<b>PEG</b>	Percutaneous Endoscopic Gastrostomy is a way of introducing a feeding tube through the abdominal wall into the stomach to provide fluid, food and medicines when swallowing has become impaired (dysphagia).
<b>PSP</b>	Progressive Supranuclear Palsy.
<b>RIG</b>	Radiologically Inserted Gastrostomy is a way of introducing food, fluids and medicines directly in to the stomach by inserting a thin tube through the skin and into the stomach.
<b>Standards of care</b>	In legal terms, the level at which the average, prudent provider in a given community would practice. It is how similarly qualified practitioners would have managed the patient's care under the same or similar circumstances.
<b>Tremor</b>	Uncontrollable shaking of the affected limbs. Can occur when the patient is resting or active.
<b>Voice banking</b>	Voice banking is a process that allows a person to record a set list of phrases with their own voice, while they still have the ability to do so. This recording is then converted to create a personal synthetic voice.
<b>Yankauer suctioning</b>	An oral suctioning tool designed to allow effective suction without damaging surrounding tissue.

**FEEDBACK OPPORTUNITY**

helpline@pspassociation.org.uk