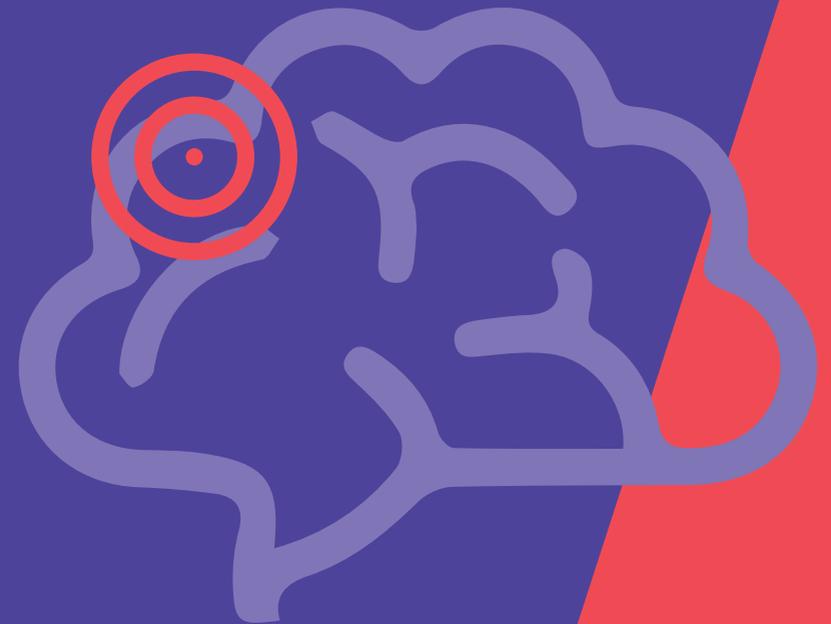




A PROFESSIONAL'S GUIDE TO CORTICOBASAL DEGENERATION



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FINDING A CURE **STARTS
HERE**

This summary guide has been developed to support all professionals working with people affected by Corticobasal Degeneration (CBD).

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

In depth information is available through the interactive resource which can be accessed via desktop PC, tablet or smartphone.

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“We are really pleased to be able to partner with CBD Solutions on this exciting initiative to design and build an interactive web resource.

It will make accessing critical information on the care of patients affected by CBD for hard pressed health and social care professionals quick and easy.

Patients will benefit from more confident and timely support, leading to better long terms outcomes. Overall, a win-win if ever there was one!

Thanks to CBD Solutions for their financial support and inspiration for the wider Pathway of Care for CBD project.”

Andrew Symons, CEO

INTRODUCTION

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

This guide was developed following a strategic commitment by PSPA to develop a care pathway specifically for those people with a diagnosis of CBD (also known as Corticobasal Syndrome, CBS). It has been written following discussions with people living with CBD and the professionals supporting them. These discussions identified that clear information was needed by:

- Health and social care professionals who support people with a diagnosis of CBD
- Those with a diagnosis of CBD
- Carers who help people with a diagnosis of CBD
- Families and friends of people with a diagnosis of CBD.

Experts in the field of CBD have contributed to this guide, alongside those with a diagnosis of CBD and their carers.

The guide is written for professionals. It may also be a helpful resource for people living with CBD, enabling them to have informed conversations with the health and social care professionals they will meet. To further support these important 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 people with CBD, 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, tablet or mobile phone.

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 CBD, their carers and family members

Health and Social Care Professionals

PSPA staff and volunteers

CBD Solutions, Sweden who funded this work

Pearce Partnership who facilitated the development of the guide

MND Association, for access to the NICE Guideline on MND (NG42)

WHAT IS CBD?

Corticobasal degeneration (CBD) is a rare, progressive neurological disease. The term Corticobasal Syndrome (CBS) is also used. However, this guide will use the more common term CBD.

KEY POINTS ABOUT CBD:

- About 5 people per 100,000 in the UK have CBD (similar to PSP and motor neuron disease, but much less common than Parkinson's disease)
- Typical age of onset is 60-70, but people may be affected from their 40's to 90's
- Life expectancy is very variable. Typically, it is in the range of 5 to 10 years, but 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 CBD
- It is caused by clumping of a protein called tau in the brain cells. These cells stop working resulting in them dying back earlier than normal
- The classical presentation is usually with one sided symptoms, with an arm or leg becoming clumsy, awkward or stiff. An unusual symptom is 'alien limb phenomenon', where one hand moves on its own
- The 'cortical' in corticobasal degeneration refers to changes in language (aphasia), speech, memory, cognition, vision, clumsiness (apraxia) and alien limb
- The 'basal' in corticobasal degeneration refers to changes in movement, which can be slow and stiff (parkinsonism) and jerky (myoclonus), with contractions/dystonia and a risk of falls

- Psychological problems in CBD can include personality changes, anxiety, depression, irritability or apathy and difficulty in making decisions (CBD 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:

- Difficulty with activities of daily living such as cutting food, doing up buttons and dressing
- Mobility problems such as 'freezing' (sudden inability to initiate a movement) and falls
- Sensory problems such as not recognising objects by their look or feel
- Progressive changes resulting in the 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.

STANDARDS OF CARE

This is a summary of the standards of care, an extended version with quality statements and suggested ways of measuring a services practice can be found on our website www.pspassociation.org.uk

BEFORE DIAGNOSIS:

- Recognition of 'Red Flags' that may point to CBD rather than Parkinson's disease, stroke, dementia or depression, including: a progressive asymmetrical presentation with stiffness, abnormal hand or foot postures, clumsy or awkward movement (apraxia), jerky tremor, and reduced and/or slurred speech
- Speedy referral to a neurologist is recommended if CBD is suspected or there is doubt about the diagnosis. Many patients with CBD are initially diagnosed with Parkinson's disease, stroke, dementia or depression, but early referral and accurate diagnosis improves the organisation of best supportive care.

AT DIAGNOSIS:

- A supporting family member or friend should be present when the diagnosis is given wherever possible
- 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 referral to the multidisciplinary team should be made.

DURING THE PROGRESSION OF THE CONDITION

COORDINATION OF CARE BY A MULTIDISCIPLINARY TEAM

- A named key worker and/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 a specialist palliative care team should be offered to assist with symptom management and advance care planning
- Patients and carers should keep an up-to-date list of their care team including names, addresses and phone numbers of their doctors, 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 CBD as well as carers and family members
- Early information about care planning including decisions to refuse treatment and appointing a power of attorney.

EDUCATION OF PROFESSIONALS

- Support for GP and health care professionals
- Education for Social Services representatives and carers
- Support for paid domiciliary 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
- Social Services team to provide information and support in using a Carer's Plan
- 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.

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 planning, including advance decisions to refuse treatment, wishes about care, including place of care and death
- Registration on GP palliative care register and available urgent care plan systems e.g. CMC (co-ordinate my care)
- 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 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 CBD 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 CBD, particularly if there are signs of communication and cognitive change. It is important for health and social care professionals to:

- Prioritise the needs of the person with CBD 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, INCLUDING MOBILITY AND FALLS

A person with CBD may first present with an asymmetric movement disorder which may have a marked impact on activities of daily living such as dressing, mobility, transfers and nutrition. The usual motor presentation is with a 'clumsy hand', from a combination of apraxia, slowness, stiffness (akinetic rigidity and dystonia). Some people report an 'alien hand phenomenon' where the hand seems to move on its own, which can be a distressing symptom for the person with CBD and their family. As the disease progresses problems usually become bilateral. Unsteadiness and frequent falls may occur and the focus 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
- 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 and a specialist powered wheelchair may be required
- The person should not be discharged from the MDT, or individual practitioner's 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
- 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 sitting/dressing. These may respond to regular splinting or botulinum toxin injections in association with intensive physiotherapy. Sometimes anti-stiffness medication may help. Parkinsonism may respond to dopaminergic medications or other drugs, under specialist supervision. Apraxia does not respond to medication.

COMMUNICATION AND SPEECH

The person with CBD may experience speech problems at an early stage in the disease. This includes loss of fluency and distorted speech. In addition, cognitive change and visual difficulties can also affect communication and social interaction. As the disease progresses difficulties with eye movement and changes to dexterity may affect the use of communication aids.

- Prompt referral to 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 communication aid assessment needs to consider motor and cognitive problems as well as lo-tech back up
- Anticipatory prescribing of equipment and referral to specialist Augmentative and Alternative Communication (AAC) centres where indicated, with consideration of voice banking
- Early discussions about Planning Ahead are essential to ensure the individuals advance care choices are documented should speech difficulties prevent these being communicated
- Family carers will need support in adapting to significant changes in communication ability towards the end stages.

SWALLOWING AND NUTRITION

Over half of those diagnosed with CBD 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. The difficulty in managing saliva can have a distressing psychosocial impact.

- 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. Yankauer suctioning may be helpful to clear oral secretions
- Any decrease in arm function will result in the need from 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 a treatment option with the person with CBD and family carers, providing appropriate information about its aims of improving quality of life and preventing the complications of

weight loss. Where indicated, discussions around gastrostomy (PEG or RIG) feeding should be had early in the disease process. Attitudes can change during the course of the illness

- Advance care planning is important with the person with CBD 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 CBD may experience problems with their bladder and bowels. 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 the 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.

COGNITIVE BEHAVIOUR, INCLUDING EMOTIONAL CHANGE

Cognitive problems 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, and are likely to increase as the condition progresses. 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 CBD may retain normal or near normal cognitive function and insight.

- Consider referral to a neuropsychologist or memory 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 and should be regularly reviewed
- 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 CBD. It is most commonly caused by infection (delirium), or medication (e.g. opiates, amantadine or dopamine agonists).

FATIGUE AND SLEEP

The person with CBD may experience problems with fatigue and, later in the disease, with their body clock, resulting in difficulty getting to and staying asleep.

- Refer to occupational therapist for advice on fatigue management strategies, including discussions regarding flexible working with any employer where indicated
- Consider sleep hygiene measures to aid falling/staying asleep. Bell call systems at night may reduce anxiety
- Hypnotic medication may help people with CBD 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 a care 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 CBD and may be a pre-diagnosis symptom. Visual problems may be mild in CBD, however they can contribute to the risk of falls and difficulty 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 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 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 CBD itself, or from co-morbidities like falls. Sensory changes may make it harder to locate pain in the body. Communication difficulties may make understanding the extent and type 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 for 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
- Supervise analgesics carefully, monitoring for increased risk of side effects like confusion.

PLANNING AHEAD

A person with CBD 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 illness. It will ensure that the person has an informed choice and can document their wishes and consider important decisions such as legal Power of Attorney. Many people with CBD have mental capacity to make decisions. 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 CBD. 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 care: family, paid carers, MDT, GP and community services. Where possible plans should also be shared with out of hours services using urgent care plan systems where available e.g. CMC
- Talking about advance decisions to refuse treatment (ADRT) is important and these signed documents are legally binding
- Those with CBD may also wish to talk about the future and when they would state that carers 'do not attempt cardiopulmonary resuscitation' (DNACPR). This should be documented and agreed
- Many people may wish to agree a power of a attorney, make a will, make arrangements for their family in the future and make plans for their funeral
- 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 our website www.pspassociation.org.uk

RESEARCH

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

- The UK has a lot of research into CBD, including national programs supported by PSPA
- They may also wish to donate their brain to research and information about CBD brain banks can be found on our website www.pspassociation.org.uk

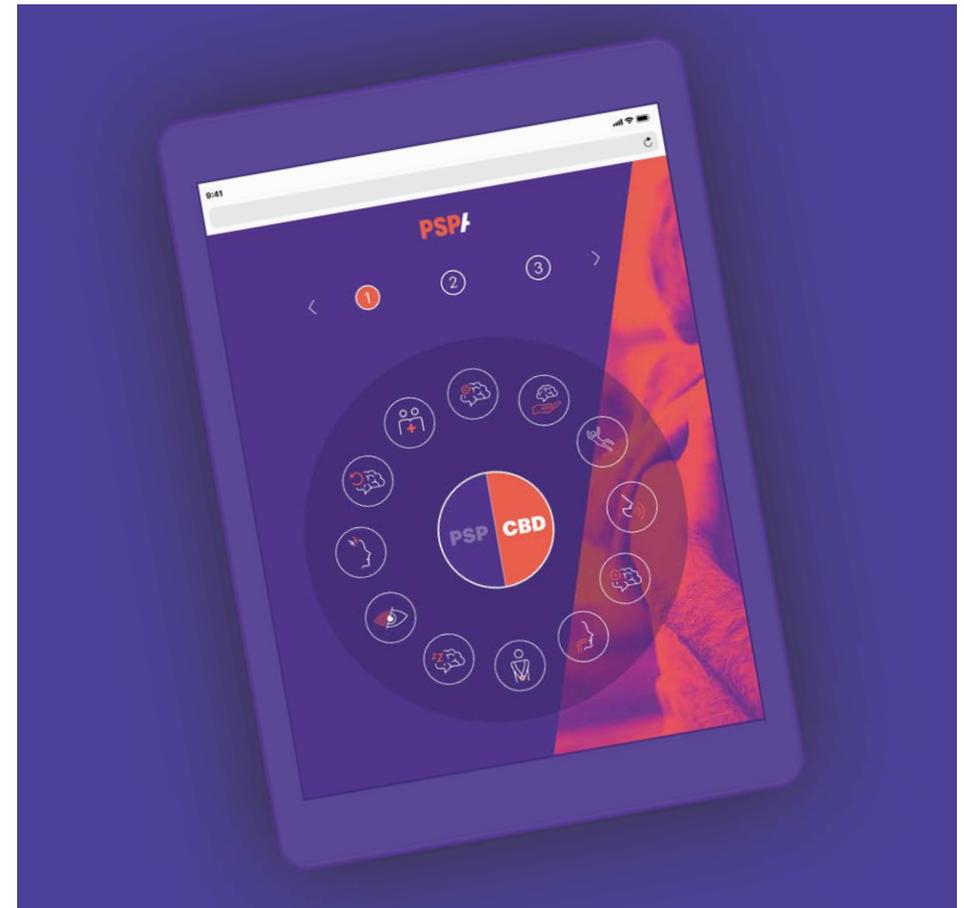
FAMILY AND CARER RELATIONS

The diagnosis of CBD 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 counselling
- Provide relevant information on Carer's Assessment, access to benefits and signpost to support networks such as PSPA, Age UK and Carers UK.

PROFESSIONALS GUIDE TO CBD

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 smartphones, tablets or desktop PC's.

www.pspassociation.org.uk

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

AAC	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.
Advance care plan	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.
ADRT	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.
Akinetic rigidity	A type of movement disorder. The major features are bradykinesia (small, slow movements), rigidity and tremor.
Alien limb phenomenon	Refers to involuntary motor activity of a limb in conjunction with the feeling of estrangement from that limb.
Anticipatory prescribing	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).
Aphasia	Inability (or impaired ability) to understand or produce speech
Apraxia	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
Assisted suicide	The act of deliberately assisting or encouraging another person to kill themselves. This is illegal in the UK.
Body clock	The body's natural need to sleep, eat, etc. at particular times of the day.

Botulinum toxin	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.
Brain bank	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.
Care plan	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.
Carers Assessment	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).
Carers Plan	Defines the care and support a carer (non-paid family member) may need to help them care for a person.
Cognition	The mental action or process of acquiring knowledge and understanding through thought, experience, and the senses.
Communication aid	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.
Comorbidity	The existence of one of more disorders or diseases at the same time.
CBD	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.
CBS	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.

DisDat	Disability Distress Assessment tool. Intended to help identify distress cues in people who, because of cognitive impairment or physical illness, have severely limited communication.
DNACPR	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.
Dysphagia	Difficulty swallowing.
Dystonia	Permanent increase in muscle tone which can restrict the mobility of the affected joint and result in abnormal posture.
Functional incontinence	The person is aware of the need to go to the toilet, but is unable to do so due to physical or mental difficulties.
Gastrostomy	A surgical procedure, creating an opening from the abdominal wall and inserting a feeding tube (gastrostomy tube).
Holistic assessment	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.
Keyworker	A single point of contact for an individual, usually a member of the multidisciplinary team.
Legal/Lasting power of attorney	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.
Mental capacity	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.
Multidisciplinary care	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.

Myoclonus	Quick, involuntary muscle jerks.
PAINAD	Pain assessment tool for use in advanced dementia.
Palliative care	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.
Parkinsonism	Parkinsonism is a term that covers a range of conditions that have similar symptoms to Parkinson's.
PEG	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).
PSP	Progressive Supranuclear Palsy.
RIG	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.
Standards of care	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.
Tremor	Uncontrollable shaking of the affected limbs. Can occur when the patient is resting or active.
Voice banking	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.
Yankauer suctioning	An oral suctioning tool designed to allow effective suction without damaging surrounding tissue.

FEEDBACK OPPORTUNITY

www.pspassociation.org.uk