

PSP

CREATING A BETTER FUTURE FOR
PEOPLE LIVING WITH PSP & CBD

**A GUIDE TO
PSP & CBD
FOR OCCUPATIONAL
THERAPISTS**



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This booklet is published by PSPA. It is part of a series of publications for health and social care professionals, to help them support people who are living with Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD).

This booklet aims to provide occupational therapists (OTs) with information about PSP & CBD and to guide and inform their practice and intervention. It also explains how the common impairments may affect typical activities and occupations. Through consultation and by drawing on evidence and literature from comparable progressive neurological conditions, the guide aims to address issues at different stages of the disease progression and to provide practical suggestions to aid therapeutic intervention.

This booklet is intended as a guide only and the information is published in good faith. It is not a substitute for the advice and experience of the consultant or other medical experts involved in the provision of care.

INTRODUCTION TO OCCUPATIONAL THERAPY

IN PSP & CBD

Whilst there is no primary research evidence to support OT intervention with PSP or CBD the value of OT in specialist palliative care services and other neurodegenerative conditions is well documented and transferable in many instances. It is recognised that OT is an important part of the multidisciplinary team (MDT) that the individual will need to access in order to maintain independence and quality of life and to manage their condition.

OT MODELS AND TREATMENT APPROACHES

Although PSP & CBD is a complex neurological condition, therapists should feel confident in drawing on their core skills to assess and understand the impact of the condition on function and all areas of daily living, utilising problem solving and clinical reasoning skills to provide effective intervention. A client centred approach such as the *Canadian Model of Occupational Performance and Engagement* or *The Model of Human Occupation*, are useful tools in understanding the individual's key issues in a holistic manner.

Motor learning theory and a task-orientated approach have been advocated in the therapeutic management of other neurological conditions. These support a functional approach to treatment in which movement patterns and components of tasks are practiced in relation to functional activities. It may be beneficial to consider using these approaches in the early stages of both conditions to minimise impairment, develop effective task specific strategies and adapt functional goal-orientated strategies to changing task and environmental conditions. In the later stages with increased and more complex impairments, on-going review, carer support and realistic goal setting and intervention needs to be based more on impact and maintaining meaningful activity and appropriate support.

Quality of life in individuals with PSP & CBD is affected due to the progressive, disabling nature of the condition and decreased life expectancy. OT intervention should focus on goals that support the individual, carers and family to try to minimise the impact of the disease, thereby maintaining their quality of life.

Intervention decisions should be made on a case-by-case basis considering the individual's cognitive status, capacity to learn and retain information,

stage of their disease, degree of impairment, the difficulty of the task, their environment, their social situation and the individual's changing needs and goals.

A Delphi study of OT for individuals with Parkinson's identified four main roles for OTs: problem solver, educator, networker and supporter. Other studies resulted in a framework for intervention for progressive neurological conditions (see fig 1).

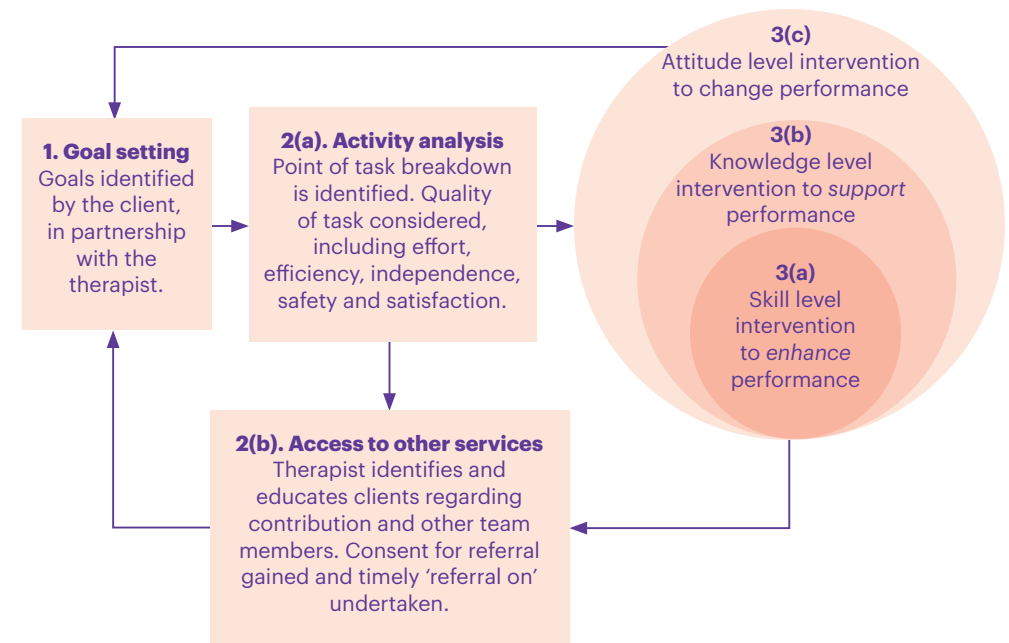


Fig 1: Framework for intervention, Jain et al (2005)
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CONSIDERATIONS FOR ASSESSMENT AND INTERVENTION

- To help strengthen your initial assessment gather as much background information as possible
- Prior to the assessment it would be worth considering what time of the day best suits the individual in terms of their fatigue
- Consider key impairments in relation to activity and participation in all areas of daily living
- Use a theoretical OT model to guide and underpin intervention
- Acknowledge and address the carer and family's needs within the assessment process
- Be mindful of the rate of disease progression and how this will influence current and future interventions
- Allow sufficient time to discuss any difficulties, taking into account their stamina, communication impairments and cognitive processing skills
- Be sensitive to their needs, returning to complete the assessment later if required
- Consider the individual's insight into their current strengths and weaknesses and how this may affect their safety
- Consider the individual's attitude to their diagnosis and acceptance of assistive equipment and services
- Establish a list of main concerns and prioritise treatment goals
- Complete appropriate referrals to colleagues from other disciplines and the voluntary sector
- Utilise the PSPA Helpline and Information Service for further support and information for the individual and their carers
- Arrange regular reviews of their needs and ensure they and their carer/family know how to contact the OT service if they have any difficulties
- Bear in mind that carers are unlikely to call for support before they have reached crisis point, which can make interventions more complex and urgent
- Consider the individual and their carer's current knowledge of the condition and its likely course and tailor initial advice or intervention to this level.

Due to the complex and multifactorial nature of these conditions, individuals and their carers should be offered an integrated assessment and planning of their health and social care needs to make informed decisions about their care. Furthermore, referral to palliative care services is recommended at the point of diagnosis.

Support from a multidisciplinary team (MDT) is essential in providing an integrated assessment and will be required throughout the disease progression.

Clear, consistent communication between health and social care professionals and the family is crucial in the provision of good quality care and addressing the individuals and any carers's needs.

Key members of the team providing support from diagnosis are shown in the diagram below and include the General Practitioner (GP), Specialist Doctor (e.g. Neurologist, Geriatrician or Movement Disorder Specialist) and Parkinson's Disease Nurse Specialists. Other key team members may include a Physiotherapist, Long Term Conditions Nurse Specialist, Speech and Language Therapist (SLT), Specialist Palliative Care Team, Dietitian, Psychologist, Social Worker/Care Manager and District Nurse.

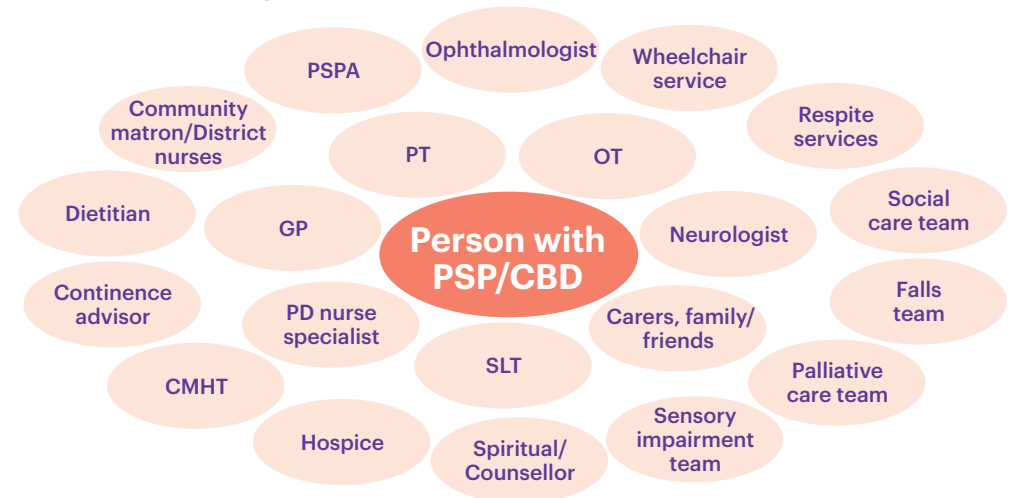


Fig 2: The Multidisciplinary team for PSP & CBD (Quine, Hurford and Morton 2008)

Key: GP General Practitioner, PT Physiotherapist, OT Occupational Therapist, SLT Speech and Language Therapist, CMHT Community Mental Health Team

A key worker system to trigger referrals and aid communication will help to ensure timely involvement of the appropriate professionals as the disease progresses.

Even if the need for individual specialist input is negligible at the point of diagnosis, the unpredictable and possibly rapid progression of symptoms means that early contact between specialists and individuals is essential.

PRESENTATION – PSP

DESCRIPTION

Progressive Supranuclear Palsy, previously known as Steele–Richardson–Olszewski Syndrome, is a neurodegenerative condition, classified as a movement disorder. It is defined by the accumulation of tau protein, which forms neurofibrillary tangles in the brain causing premature death of the neurons. The principal areas of the brain affected are:

- The basal ganglia (particularly the subthalamic nucleus, substantia nigra and globus pallidus)
- The brain stem
- The cerebral cortex
- The dentate nucleus of the cerebellum.

ONSET

Early symptoms may include:

- The inability to look up or down (known as a supranuclear vertical gaze palsy)
- Initially vertical eye movements may be slowed
- Parkinsonism (‘extrapyramidal symptoms’ of slowness and stiffness)
- Often symmetrical and predominant stiffness in the neck
- Falls – often backwards
- Striking facial appearance often with frontalis overactivity (‘startled expression’) and reduced blink rate
- Cognitive dysfunction.

EPIDEMIOLOGY

- Unlikely to occur below the age of 40 – average age of onset is 62
- Median interval between onset and diagnosis is three years
- Slight male predominance in most studies.

INCIDENCE AND PREVALENCE

Prevalence: 6 per 100,000 – This constitutes around 5% of parkinsonian patients seen in the movement disorder clinic.

DIFFERENTIAL DIAGNOSIS

To date, definitive diagnosis of PSP can only be made by post mortem examination of the brain. Specialists can make the diagnosis with over 90% accuracy.

The initial symptoms can present as idiopathic Parkinson's and it may be some time before development of the symptoms that lead the neurologist to suspect PSP. Some patients may wait two – three years before diagnosis of PSP is reached.

Cianci (2012) suggested a useful acronym to aid differentiation between Parkinson's disease and PSP – **FIGS**

F – Frequent falls, generally backwards

I – Ineffective medication, Parkinson's disease medication generally doesn't work

G – Gaze palsy

S – Speech and swallowing changes

No diagnostic tests exist but imaging techniques including SPECT, PET and MRI scans are carried out primarily as a means to exclude other neurological conditions. An MRI scan can show the presence of the 'hummingbird sign' in some people with PSP. The 'hummingbird sign' is an indication of midbrain atrophy which has been shown to be reliably predictive of PSP.

PSP is a very individual condition, with a wide variation in symptoms and rate of progression requiring increasing care and support from the multidisciplinary team.

PRESENTATION – CBD

DESCRIPTION

Corticobasal Degeneration (CBD) is a progressive neurological disorder characterised by nerve cell loss or deterioration and atrophy of multiple areas of the brain. The progression of the disease may be slower than the progression of PSP. It is defined by the accumulation of tau protein, which forms neurofibrillary tangles in the brain. Many of the management interventions for PSP are often helpful in CBD.

The principal areas of the brain affected are:

- The basal ganglia
- The cerebral cortex.

People diagnosed with CBD may occasionally go on to develop features of PSP and vice versa.

ONSET

Early symptoms may include:

- The inability to use one side of the body, for example the loss of use of one hand
- Myoclonus and apraxia (jerky, awkward movements)
- Complex unintentional movements of the limb interfering with normal tasks ('alien limb')
- Increased behavioural changes
- Problems with memory
- Asymmetric – not occurring equally on both sides of the body.

EPIDEMIOLOGY

- Can affect people from 40 onwards – average age of onset 60 – 70
- Slightly more common in women.

INCIDENCE AND PREVALENCE

- Prevalence: 5 per 100,000.

AETIOLOGY AND TREATMENT

DIFFERENTIAL DIAGNOSIS

Differential diagnosis is as PSP.

FAMILIAL

Less than 1% of those with PSP have a family member with the same condition. A variant in the gene for tau protein called the H1 haplotype, located on chromosome 1, has been linked to PSP, but this genetic variation is common and is not enough to cause PSP on its own.

The role of genetics in PSP is currently under investigation, but the likelihood of the condition being passed on through genetic mutations is very small.

CAUSES

Despite the recent advances in the understanding of the biology of these diseases, the cause of the disease is still unknown.

Almost all cases appear to be sporadic. It has been suggested that both environmental and genetic influences may be involved. Around 20 percent of the UK population carry a gene which provides a weak susceptibility to PSP (though with a very low level of risk), but the disease itself appears to be triggered environmentally or selectively.

TREATMENT

There is currently no treatment or cure for PSP or CBD. Management is based around symptom control and quality of life hence early diagnosis and referral to specialist multidisciplinary teams is key.

More information on the causes and treatment of PSP & CBD can be obtained from the PSPA website www.pspassociation.org.uk

IMPAIRMENTS

Impairments in PSP & CBD occur and progress at different stages and rates, with the combination and intensity varying for each individual. Some of the impairments are common in both conditions and some are specific to each one. Below are common impairments to be aware of:

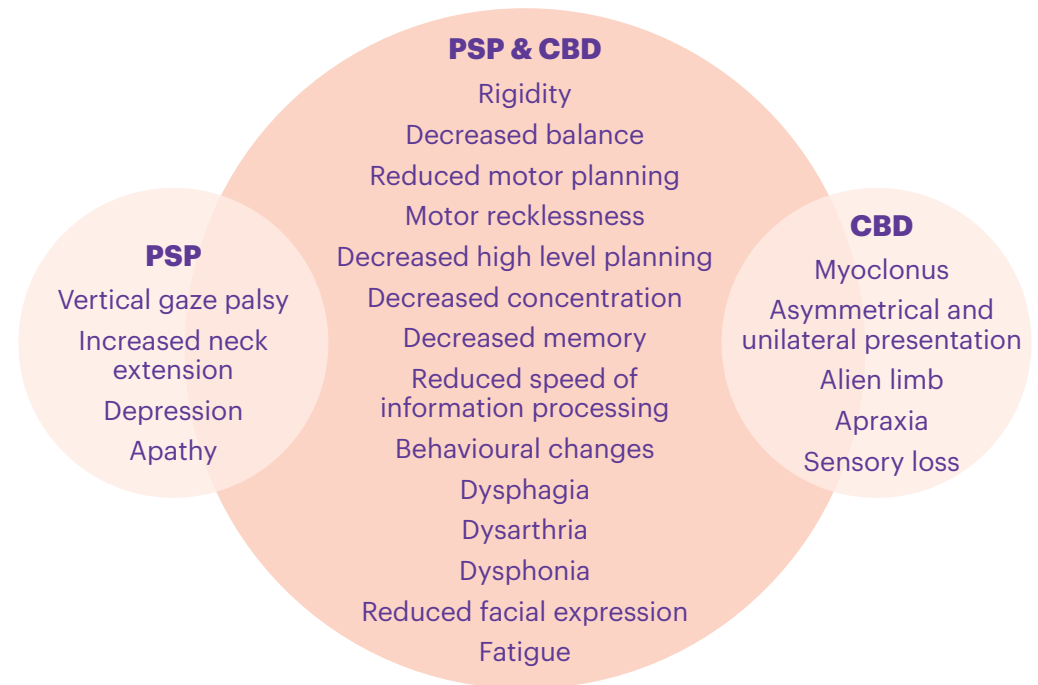


Fig 3: Common impairments in PSP & CBD (Hurford, Morton and Quine 2008)

Data from Burn and Lee, 2002 and Welling et al 1998

Symptoms become increasingly severe as the diseases progress, and a referral to the local specialist palliative care team should be initiated early on in the disease process even though their direct support may not immediately be required.

OCCUPATIONAL THERAPY INTERVENTION

EARLY STAGE (INCLUDING DIAGNOSIS)

As with other progressive neurological conditions, people's reactions to a new diagnosis can vary significantly. The individual may experience a variety of emotions ranging from fear of the future, anger, denial and hopelessness through to acceptance. Due to the complex nature of the condition, a definitive diagnosis is often delayed. Symptoms may already be affecting the individual's performance and a degree of acceptance and adjustment may have already begun. The reactions, emotions and coping of those around them will also affect the person's response to their diagnosis.

In considering the framework for OT intervention, the OT role as an educator and networker are discussed for this client group:

EDUCATOR

Condition specific advice

Therapists working with individuals with PSP & CBD do not need to be experts in the area to provide basic advice on the condition. It is however important for the OT to have a basic understanding of the types of symptoms that are likely to be experienced through the progression of the disease and the time frames in which these may occur. In understanding this, it will enable them to judge where the individual is considered to be within this process and plan intervention accordingly. However, whilst it may be useful to plan ahead for the individual's future needs, this can often be difficult for the individual or family to accept. You should be sensitive in how this is approached and also recognise that in the early stages they can be overwhelmed by the information and the number of health and social care professionals involved.

OTs should provide support and information to people living with both conditions so they can make informed decisions about their care and treatment.

Resources and information

When newly diagnosed the individual and their carers often have limited knowledge of health, social care and charitable resources available to them. At this stage, they should be directed to PSPA, which is a key resource in providing valuable information, support and practical advice. A key role of the OT at this stage is to provide information on community services and

resources that may help them throughout the disease process as well as providing a clear explanation of the role of OT and a means of contact. Areas to discuss include support provided by their local authority, benefits, community transport, Blue Badge Scheme, The Disabled Living Foundation, equipment suppliers, local voluntary sector services and any other support available locally (e.g. hospice, support groups).

Driving

Newly diagnosed individuals with PSP or CBD should contact the Driver and Vehicle Licensing Agency (DVLA) and their insurance company to inform them of their diagnosis as soon as it is confirmed as impairments may affect their safety to drive. This is a legal requirement.

The individual should be reassured that reporting the diagnosis to the DVLA does not necessarily mean that their driving licence will be withdrawn. The DVLA will conduct an assessment from the information provided by them and their medical team. They may request attendance at a driving assessment centre before making a decision.

NETWORKER

Referrals to other agencies

It is important that the person's longer-term needs are considered and the appropriate referrals are made early within the disease process to community services and third sector organisations. Agencies should be made aware that referrals are urgent because the condition is likely to progress rapidly. In some local areas there may be well established existing pathways for individuals with these conditions, try to identify whether there is anything available locally so that this can be accessed as soon as possible.

ACTIVITIES OF DAILY LIVING (ADL)

In the early stages of the disease individuals are likely to be independent and able to sustain most activities of daily living, but these will often be more effortful. Therefore, advice on fatigue management strategies to assist them in planning and prioritising their ADL is useful. Complex or fine motor tasks may become difficult and it is important to address these within OT assessment.

MID STAGE

Functional assessments within specific tasks are required in order to trial and identify the most suitable strategies or assistive devices at this stage. Keeping recommendations simple is often most effective. Try not to overload individuals with lots of equipment at this stage.

Individuals with CBD often present with a progressive asymmetric rigidity which will make bilateral ADL difficult. These difficulties can be further compounded by apraxia, and it is important to problem solve impact on function and to support family and carers' understanding.

WORK

CBD may be diagnosed as young as 40 years, and although PSP is often diagnosed later in life, support in the work place and managing their working role may be a priority or concern for the individual. Key areas for OT intervention may include:

- Support and advice on continuing to work if this is important to the individual and is a realistic objective
- Support regarding the disclosure of their diagnosis to employers and colleagues
- Exploring difficulties in the work place to identify reasonable adjustments to the environment or role that optimises their performance. These may include adapting their work area and computer, assistance with travel, introduction of frequent breaks and support within the work place
- Signpost to work resources such as the Access to Work Scheme
- Advising on rights and responsibilities under the Equality Act (2010)
- Maintaining a balanced view of the employee's need to work with the employer's need to maintain a productive service
- Reviewing satisfaction with work-life balance
- Advising on applications for benefits if this is appropriate and signposting to Job Centre Plus, benefits advice services and the Department of Work and Pensions (DWP) Visiting Service via the PSPA helpline.

People with PSP & CBD often experience a moderate level of disability and require OT intervention before a definitive diagnosis is confirmed. Individuals are likely to have increasing difficulties across a range of activities of daily living and although they may not be able to carry out all the elements of a task, it is important to maximise their participation to maintain a sense of self-worth and competence. The following tasks will be important to assess and consider.

TRANSFERS

Clinical reasoning to identify appropriate strategies and equipment to support safe transfers is essential and will need to consider the person, environment, support available and the task. People with PSP struggle with transfers due to limb and trunk rigidity, lack of cognitive planning for the task, vertical gaze palsy, impulsivity and increased neck extension. 'Sit to stand' is especially difficult from low surfaces and they will often drop back into the chair when sitting (sit 'en bloc') making them at risk of hitting their head if a chair is against the wall. When standing up, the 'rocket sign' is evident as they may race off in an unsteady manner, putting them at risk of falls.

People with CBD will also struggle with transfers due to rigidity, apraxia, cortical sensory loss and sometimes alien limb behaviour. For both groups a thorough assessment of transfers in the home setting will be necessary.

Assistive equipment such as chair raisers can be helpful, along with providing advice to the individual and others involved on safe transfer techniques. For example focusing on slowing down, good alignment and executing the transfer using normal movement patterns, is an essential component of the treatment. Breaking down complex movements, such as sit to stand, can be improved using strategies where each component part of the task is treated separately e.g. for sit to stand: bottom forward, feet placed, hands placed, chin forwards and UP. The last component becomes increasingly difficult as PSP progresses. However, due to impairments with judgement and reasoning, individuals may not always retain techniques practised or information about how to use equipment in the first instance, so repetition is likely to be required. It is therefore important for the OT to consider this when making recommendations, as equipment may not always be the most appropriate

option to optimise function. Also, equipment needs may change frequently due to the progressive nature of the condition.

An important part of the role of the OT is to educate carers about moving and handling techniques, the importance of caring for their own backs and their role in reiterating taught strategies.

GUIDANCE FOR TRANSFERS

Chair transfers

- The provision of handling belts, for carer use, can increase the amount of control they have during transfers
- Raise the chair to an appropriate height, aiming for at least 90 degrees at the knee
- Ensure the chair is stable and that armrests are at a suitable height/position to enable the individual to push up (remember individuals with CBD may only be pushing up with one arm)
- Educate the individual and carer on 'sit to stand' techniques, emphasising controlled normal movement, strategies and even weight distribution to facilitate standing and how to reduce risk to themselves
- Verbal or written prompts, including cue cards, can be helpful to remind the individual to slow down and use normal movement principles during transfers
- If the individual still struggles with 'sit to stand' consider the use of a riser recliner chair
- Ensure the environment is safe and there is sufficient area around the chair with no obstacles or trip hazards
- Take into account visual impairment related to PSP.

Bed transfers

- The use of a bed lever or bed stick can be beneficial to aid rolling and rising in bed
- A satin half sheet or glide sheet placed at the mid third of the bed can also be useful with turning and rolling in bed, as it reduces friction. However, careful consideration should be given as this may contribute to the person's risk of falling during transfers
- Educate the individual and carer on bed transfers and cues. Breaking down the transfer into rolling, dropping legs off the bed and pushing up into sitting
- Consider the height of the bed, location within the room, the space around the bed and the floor surface.

Toilet transfers

- Be aware of the impact of motor recklessness (individuals appear to be unaware of their poor balance, and mobilise quickly and unsafely) and rigidity when assessing the appropriate equipment
- Freestanding toilet equipment will probably be inappropriate due to the risk of falls
- Consider how continence issues such as increased frequency, night time toileting, and decreased speed of accessing the toilet can be managed
- Wheeled toileting equipment (e.g. commode seats that wheel over a toilet) can be of benefit in reducing the number of transfers and the amount of mobilizing required. Ensure these have a padded seat, wherever possible, for individuals who are losing weight
- Wash/dry toilets (such as Closomat) can help maintain independence for personal hygiene. The use of wet wipes rather than dry toilet paper, can also make the process easier.

Bath transfers

- Assess the safety of appropriate bath equipment, taking into account the potential impact of rigidity, wandering limbs, reduced visual field, backward falls and motor recklessness
- Bath boards would probably be inappropriate due to risk of falling backwards
- Trial the use of a swivel bather or an electronic bath aid with a supportive seat, however these may only be a short-term solution due to the rapid progression of the disease
- Consider early referral for major adaptations such as a level access shower to enable continued bathing as other options may soon become unsafe.

Car transfers

- Educate the individual and carer on positioning the car to allow the door to be opened fully and to transfer onto an even surface of appropriate height
- Educate the individual and carer on car transfer techniques i.e. getting legs square against the seat prior to sitting down
- A firm cushion may be used to raise the height of the seat or a wedge to level off a sloping seat
- A clip-on handle to the car door to aid transfer or a flexible fabric turning-disc with a non-slip base may be useful aids to trial, to assist with moving legs in and out of the car with supervision and in accordance with the manufacturer's guidelines
- If car transfers become increasingly difficult and unsafe individuals may wish to travel in a wheelchair taxi or consider adapted cars with support from their regional driving assessment centre.

PSP damages the regions of the brain associated with balance control, often leading to slowness in movement, motor recklessness - particularly in sitting and standing up, muscle rigidity, and deterioration in posture, gait and stamina. However, despite the rapidly progressive nature of the condition, rehabilitation and education may help to maintain balance functions and slow the decline in mobility.

Individuals with CBD present with unilateral and asymmetrical onset of impairments that have different functional implications for mobility than PSP. The loss of use of one hand will impact on ability to use a walking frame. As CBD progresses, it is no longer asymmetrical and mobility will need to be reviewed regularly. In common with PSP, there may be a disturbance of eye movements.

Physiotherapists are expert at assessing mobility and suitability of mobility aids. It is important that OTs liaise closely with their physiotherapy colleagues to discuss the functional implications of mobility within the individual's different environments and tasks in order to optimise safety. In addition, physiotherapists would be able to provide advice on appropriate exercises to maintain and maximise function and reduce the risk of further complications such as spasticity.

Problems with mobility can be compounded by a motor recklessness, which means individuals may appear to be unaware of their poor balance, and mobilise quickly and unsafely.

If the individual has problems with vertical gaze palsy, (a common problem with PSP) then they will be unable to look down and scan for hazards as they mobilise.

Home environment

Education around the set-up of the home environment is essential for the individual and the carer to aid safe mobility. This should include:

- Adequate space for mobility aids and turning circles
- Clear pathways and minimisation of trip hazards such as loose wires and rugs

- The padding or removal of sharp edges and hard surfaces in likely fall areas, as it is unlikely that falls can be prevented totally
- The use of static rails and grab handles within the home can be easier for individuals to use over mobility aids.

Wheelchairs

As their impairments increase difficulties with mobility can become stressful for family and carers. A wheelchair may be a beneficial option but the decision can be seen as a loss of mobility and independence and an indication that they are deteriorating. It is important to support them to see the positive impact on quality of life that using a wheelchair can have as it allows them to access activities and places further afield from the home and can increase safety.

Provision of powered wheelchairs should be considered with caution due to changes in eye gaze and in cognition. However, if provided at an early stage they can prove useful to some individuals when given the correct support, training and ongoing review.

Stairs

Often a stair lift may not be the most suitable long term solution for the individual. Both conditions can often progress quickly to a stage where it is unsafe for the individual to transfer on and off at the top and the bottom of the stairs.

The combination of backward falls and difficulty with downward eye gaze in PSP makes stairs a particular hazard. Assessment of safety on stairs will need to be completed and recommendations made accordingly, for example, a second stair rail or major adaptations. Alternative solutions such as a bed being brought down stairs, a through floor lift, one floor living or the support of a carer to supervise stair mobility would be useful to consider. Support with applying for rehousing may sometimes be required.

Guidance for mobility aids

- Consider a neurological physiotherapy referral for a period of rehabilitation and education. Complete a comprehensive assessment of stairs and mobility (with physiotherapy colleagues if possible)
- Weighted walking frames have been suggested as a useful mobility aid for people with PSP. An example is the 'U step', a reverse braking mobility aid using the concept of shifting weight forwards to reduce the risk of falling backwards when holding onto the frame. However, there is currently no primary evidence to support the effectiveness of weighted walking frames and their provision will need to be considered on an individual basis. These are not yet routinely available through statutory services and a special order or funding may need to be obtained
- People with CBD may require mobility aids that only require the use of one hand and arm
- Built up/wedge shoes that help shift the weight forwards with the aim of reducing falls backwards have been suggested by some people with PSP. However, there is limited primary evidence to support the use of wedge shoes and caution should be exercised, considering the person's mobility and safety at times when they may not be wearing the shoes such as night time toileting or at the beginning of the day
- In view of CBD related cognitive impairments, wall fixed rails around the home environment may in some cases provide a more effective solution for mobility problems
- Assessment within the home environment is key to the identification of appropriate solutions
- Referrals for wheelchairs should be made as soon as possible. An explanation should be given about the sometimes lengthy wait for provision, and therefore the need to organise this some time before it is required. Individuals may feel comfortable with this if the wheelchair is provided 'just in case'
- Carers should be given advice and training on correct wheelchair use for care of their backs. This should include how to ascend/descend kerbs.

Falls backwards and sometimes sideways are a significant problem for people living with PSP. Individuals who experience frequent falls in the early stages of the disease are likely to have a faster progression in the severity, although it is important to remember that from symptom on-set to diagnosis there can be a significant delay.

Falls are often sudden and without warning, and individuals with PSP are at high risk of skull and rib fractures, unlike Parkinson's where hip fractures are most common due to the direction and rigidity during the fall. In addition, the presence of visual impairment clearly heightens their falls risk and probability of injury. Trauma as the result of backward falls is the main cause of death in early PSP.

Falls are a major consequence of the disease and become a constant part of the individual's and carers' lives. As such, it should be a priority during OT assessment and intervention. It is important to recognise the stress for carers related to the high risk of falls combined with impulsive behaviour.

Guidance for fall management:

- Early referral to falls management group/team
- Referral and liaison with physiotherapy colleagues
- Education on getting up from the floor for individual and carer within the home environment, including appropriate equipment and demonstration of techniques
- Advice on equipment available such as pendant alarms and telecare systems, including bed and chair alarms
- Education to the individual and carer to concentrate on one task at a time to reduce the risk of distraction when mobilising and transferring
- There is currently limited evidence to support the effectiveness of protective garments such as helmets and hip protectors, and these should be assessed on an individual basis
- Consider whether any equipment the individual has is increasing falls risk, for example riser-recliner chairs and free standing toileting equipment.

The OT has a significant role in educating formal and informal carers on the optimal conditions for maximising independence with eating. This may be within the home, hospital or care home environment.

The characteristics of severe vertical gaze palsy and cervical dystonic neck posturing into extension are distinguishing symptoms of PSP. These can affect a person's ability to see and locate food on the plate in order to load the spoon/fork and bring it to the mouth, as well as increasing the risk of aspiration when swallowing.

Joint assessments with SLT colleagues are essential to determine the individual's swallowing abilities and risks.

Review their posture, seating and the environment before exploring aids to bring the plate within the individual's visual field.

Apraxia, myoclonus and alien limb behaviour may impact on the planning and coordination of eating and nutrition for individuals with CBD and this should be addressed within your assessment.

In addition, assistance from carers may be required to overcome these problems. The involvement of a dietitian would be helpful to ensure nutritional needs are being met.

Guidance for eating

- Consider the height and positioning of the plate or bowl and the surface in relation to the person's visual field. A variable height table may be useful
- Refer to a dietitian if there are issues of weight loss, adjusting and managing their new diet or other concerns regarding nutritional or fluid intake
- Consider trialling the use of prism glasses during meals. Prism glasses lower the individuals' visual field, and are available from PSPA
- Screen for any swallowing difficulties and refer to SLT as appropriate
- Plate guards or a high straight edge bowl can provide additional sensory input when loading the fork or spoon
- Insulated bowls and plates may be useful for individuals who take time to eat independently

- Adapted cutlery such as angled or splayed forks can make it easier to get food into the mouth when wrist/forearm movement is limited
- Liaise with physiotherapy colleagues to assess the impact of the individual's seated posture on eating as a specialist seating system may be required
- Consider the effects of the environment as potential distractions may impact on the individual's ability to focus on eating
- For individuals experiencing more severe alien limb syndrome consider one-handed strategies and equipment such as a rocker knife and the use of dycem mats or other non-stick materials
- Encourage family members to describe to the individual where food is on the plate and reiterate this during meal times
- Having food cut up by a family member and/or finger food can be easier to manage and maintain independence with eating for longer periods.

Assessment of personal care will be required, taking into account the main impairments experienced such as motor recklessness, vertical gaze palsy and processing difficulties in PSP, and apraxia, myoclonus, involuntary movement and alien limb in CBD.

Assessment, intervention and review should be ongoing, in order to adjust the level of assistance needed.

A person centred approach should be maintained as being able to participate in elements of a task can contribute to the individual's self-esteem and quality of life.

Guidance for personal care

- Angled mirrors in the bathroom may aid the individual's ability to search and locate items needed and to self-monitor grooming tasks such as shaving and cleaning teeth
- Provision of appropriate seating will help to minimise the risk of falls
- Velcro fastenings or elastic waistbands may make dressing and undressing easier
- Consider how involuntary movement may impact on safety and use of tools within tasks
- Keep surfaces and work environments as clear and free from distraction as possible
- Consider alternative toiletry items to reduce the complexity of task such as pump action toothpaste and soap, electric toothbrushes and razors
- Lower half dressing aids may be of benefit, such as sock aids and long handled shoehorns
- Provide advice and assistance to carers on how to supervise, prompt and assist the individual. This might include:
 - Reducing visual and auditory environmental distractions
 - Breaking down the task into simple steps
 - Providing short simple verbal prompts
 - Allowing extra time for responses to prompts and the completion of each stage

FATIGUE MANAGEMENT

- Early referral to social care for support and a Carer's Assessment may help to ease the carer's strain and risks
- Consider referral to a district nurse or continence nurse specialist if continence issues are affecting their quality of life or increasing their risk of skin problems and infection
- Consider that personal care ability can also be affected by the person's apathy and fatigue
- Give the individual plenty of time to complete personal care tasks. Often breaking tasks down into chunks, so sections can be done at different times of the day, is beneficial
- Simplify clothing wherever possible to maintain independence. For example avoiding items with zips and buttons, or purchasing clothes a size larger.

Fatigue can be a common symptom of both PSP & CBD and should be recognised and addressed as part of OT intervention.

Fatigue is a 'non motor symptom' and is often seen as an 'invisible symptom'. It will often exacerbate other symptoms associated with the condition. It is likely to make dealing with everyday activities more difficult, therefore it is important that fatigue and its management are carefully considered. Fatigue management requires a coordinated approach with the individual's active participation and involvement from their family and friends as well as health care professionals.

As distinguished from severe tiredness, fatigue can have a devastating effect on a person's ability to maintain normality.

It can affect:

- Ability to carry out all activities of daily living
- Cognitive ability
- The individual's attitude to their illness and treatment
- Speech
- Psychological wellbeing and self-image
- Relationships
- Sexual function
- Mood.

Fatigue can exacerbate or contribute to other symptoms and managing it is important to well-being and quality of life. There is a close relationship between fatigue and depression. It is important that both are assessed and treated appropriately. Medication can help with a person's fatigue but a non pharmacological approach to support the individual and their carers can be effective.

RECOGNISING FATIGUE

Clinical assessment to rule out other possible causes of fatigue such as anaemia or malignancy is important. If a person has 6 or more of the 10 symptoms below they could be living with fatigue:

- Diminished energy, or increased need to rest, disproportionate to any recent change in activity level
- Complains of general weakness or limb heaviness
- Diminished concentration or attention
- Decreased motivation or interest to engage in usual activity
- Insomnia or hypersomnia
- Experience of sleep as unrefreshing or unrestorative
- Perceived need to struggle to overcome inactivity
- Marked emotional reactivity to feeling fatigued
- Perceived problems with short-term memory
- Post-exertional malaise lasting several hours.

WHAT CAUSES FATIGUE

It is unclear what causes fatigue in PSP, but it is likely to be linked to other symptoms and can be experienced as a result of a number of factors. These include:

- **Medication** – Many medications may cause tiredness or drowsiness as a side effect. It is important to be aware of this and the individual should be encouraged to discuss any concerns with their GP if they notice a correlation between a change in energy levels and a change in medication
- **Infection** – Infections such as a cold or urinary tract infection are often associated with increased tiredness and should be treated proactively
- **Sleep disturbance** – Sleep disturbance impacts on energy levels during the day. This may be due to symptoms that can be alleviated or reduced, for example, pain, urinary urgency at night, depression or anxiety. These symptoms should be highlighted for treatment by the appropriate MDT member
- **Environment** – The lighting and temperature within an environment are crucial, as poor lighting increases visual effort and extreme noises or temperature can exacerbate fatigue. It is also useful to consider the physical demands of the environment for example access and distance

- **Exertion/deconditioning** – The increased effort required by the body if mobility or coordination is affected can cause fatigue. Reduced activity can also lead to deconditioning of both the cardiovascular system and the muscles themselves, thus resulting in less efficient use of energy and an increased experience of fatigue. This should be discussed with the individual and a referral made to physiotherapy as appropriate
- **Depression/low mood** – Low mood can affect an individual's motivation to be active and make them feel lethargic. This can lead to a vicious cycle of reduced activity, deconditioning, increased fatigue and ongoing low mood. Therefore it is important to address mood within fatigue management.

GUIDANCE FOR FATIGUE MANAGEMENT

- Develop the individual's and carer's understanding of fatigue to support self-management, choices, planning and prioritisation of tasks. Completing a fatigue diary with support from carers, if needed, can be a useful way to do this
- Affirm and build on their natural adaptive coping skills and establish activity baselines - what they want to do and what they have to do
- Support prioritising, pacing and maintaining activities; avoiding activities that could be completed by other people
- Consider discussing additional help for domestic and personal care activities, enabling individuals to use their energy for the activities and roles that are important to them
- Support individuals to consider activities in order of priority. This might include a weekly timetable spreading heavy and light tasks and planning for rest periods, social activities and appointments
- Support individuals to adapt and grade activity, considering the use of assistive equipment and aids to maximize their energy use, independence, safety and confidence
- Support effective environmental organisation/use of ergonomics in the home to allow efficient use of energy and therefore reduce fatigue. For example, items in regular use should be within easy and safe reach

- Allowing time to rest is important when planning a day's activities. Frequent short rests are more effective than one long rest. Ideally rest breaks should be taken at regular times, before feeling tired. It can be useful to help the individual to identify a relaxation method that suits them to use during their rest periods
- Provide postural advice to enable activities and rests to be carried out in the most relaxed and efficient ways possible, minimizing stress on the body
- Exercise balanced with rest is an important part of fatigue management. Liaise with physiotherapy colleagues for specific levels and types of exercise and also for access to local exercise services
- Consider the impact of anxiety on fatigue and address with anxiety management strategies if appropriate
- Support individuals to simplify, delegate or eliminate tasks from their day to reduce energy demands and educate family members as to why this is beneficial.

People with PSP & CBD are likely to experience a range of communication difficulties. This can be due to decreased volume of speech, dysarthria, fixed facial expression, inability to gain eye contact due to vertical gaze palsy, fatigue, decreased speed of information processing and difficulty with excessive saliva production. These symptoms can give the inaccurate impression that the individual is disinterested in conversation. It is important that everyone involved understands this.

Communication issues also include difficulty with handwriting, typing, using a telephone and using a computer.

Bear in mind that people with PSP can become withdrawn and apathetic which will affect their communication. This should be considered during assessments and discussions with carers as this can often be a source of frustration and a sense of loss for the individual.

Guidance for communication

- Liaise with SLT colleagues about communication strategies and potential aids. The OT's role may involve how to maximise movement and positioning to best utilise communication aids. Due to gaze palsy and cognitive deficits AAC (Alternative and Augmentative Communication) equipment may not be suitable
- Educate carers, family and friends and address any frustrations, supporting them to continue with effective communication. Develop their understanding and use of coping strategies when communication is difficult, especially where behavioural or cognitive changes are also present
- Allow extra time for responses to questions
- Ensure that your questions are appropriate and accessible, especially if the individual has cognitive or behavioural impairment
- Reduce distractions during sessions
- Try to gain eye contact during communication wherever possible
- Split sessions into manageable time lengths to avoid the impact of fatigue on their communication
- Provide cognitive handwriting strategies to increase written letter/word size, if this is relevant. Trial different size pens, grips and pen nibs to see what works

- Encourage individuals to sit down when using the telephone to reduce the risk of falls
- In conjunction with physiotherapy colleagues, ensure that the individual's head and neck position is not obstructing their ability to communicate
- When appropriate, facilitate discussions on advanced care planning which may become increasingly difficult when communication is impaired. Lasting Power of Attorney and other documentation may also be appropriate.

Vertical gaze palsy is a key clinical sign of PSP. Other impairments may include blurred or double vision (diplopia), reduced blink rate and tearing, photosensitivity, interrupted smooth tracking and steady gaze and reduced ability for the eyes to converge.

Chronic eye irritation related to reduced blinking and tear duct impairment can cause distress which may result in individuals keeping their eyes closed for comfort. It is important that this is recognised as it will affect engagement in ADL and it is easy for people to presume individuals are sleeping rather than resting their eyelids.

Assessment by the neuro ophthalmologist and neuro optometrist is very important and this should be requested by the individual's team.

Double vision can be treated by patching one eye or putting tape over one lens.

Where people are struggling with blepharospasm, botulium toxin injections may be indicated and for apraxia of eyelid opening lundt loops or ptosis crutches may be helpful.

In common with PSP, people with CBD may have disturbances of their eye movements, although it is less striking than with PSP and paralysis of vertical eye movements is uncommon. With both PSP & CBD the OT's role should focus on practical strategies to manage the impact of visual impairments.

The ophthalmology team may register the individual as sight impaired, or for those with severe bletharospasm, as severe sight impaired, entitling them to free 'talking books' and 'talking newspapers' services.

Guidance for visual impairment

- Advise on the benefits of good lighting within the home environment
- Ensure walkways and work surfaces are clutter free
- A trial of prism glasses can be useful for table-top tasks only. They are not recommended for use when mobilising
- Assess the impact of visual colour contrast within the home. Flat colours are easier to see, so changes to wall surfaces and carpets may be advisable
- Trial downward tilted mirrors in areas such as the bathroom and kitchen as they may be useful to counteract vertical gaze palsy when carrying out tasks

COGNITIVE CHANGES

- Use of bookstands that hold reading material at eye level may be useful
- Registering as blind or partially sighted may be appropriate
- Referral to the local sensory impairment team may be beneficial if vision is significantly affecting functional ability and safety in the home as equipment can be provided
- Provide advice on resources such as talking books or newspapers, assistive technology, digital books (font sizes can be enlarged) and computer applications
- Be aware of the social impact of visual impairments and adjust the environment and activities accordingly
- Assist the individual to engage in alternative hobbies and interests that aren't visually loaded.

'Cognition' refers to mental processes such as memory, understanding, language, vision and thinking. The brain is made up of four parts, known as the frontal, temporal, parietal and occipital lobes, which are used for cognition.

Cognition can be separated into four areas:

- **Executive function** – involves the skills required for problem solving, responding to new situations, shifting attention, initiating and stopping movement and motivation. Executive functions also help us with memory and are based mostly in the frontal lobe
- **Language** – includes understanding written and spoken words and expressing our ideas in speech and writing. It is based mostly in the temporal and frontal lobes
- **Memory** – includes learning and making new memories, storing memories and getting access to old memories when we need to. These functions mostly use the temporal lobes
- **Vision and perception** – the skills required when dealing with the information gathered by your five senses. Many of these functions use the temporal (hearing), parietal (touch and 3D) and occipital (vision) lobes.

There are a wide spectrum of cognitive changes in PSP & CBD. Some people experience very mild changes, while for others the changes can be more pronounced. A small but significant minority of people living with PSP may experience severe changes in cognition, behaviour and personality.

You may also wish to refer to *A Guide to Cognition for Health and Social Care Professionals*.

PALLIATIVE REHABILITATION

A palliative rehabilitation approach can help people achieve their physical, social and emotional goals, maintain their independence and dignity and help them to adapt to their condition as well as giving back a sense of control. It does so against a background of helping people facing major changes and loss of future plans and expectations. Timely and flexible access to rehabilitation services is beneficial and goals need to be realistic and based on the wishes of the individual and their family.

Guidance for palliative rehabilitation

- Realistic goal setting
- Assist people to achieve their chosen level of function within their physical, psychological or emotional abilities
- Assist psychological adjustment to loss of function or lifestyle
- Consider fatigue, stress and anxiety management
- Explore relaxation techniques to reduce pain, breathlessness or anxiety
- Environmental assessment
- Provision of equipment or adaptations to enable optimum independence
- Assessment and prescription of wheelchairs, pressure relief and seating needs, including more specialist wheelchair systems (e.g. tilt-in-space seating)
- Provide postural support for existing standard seating wherever possible, using cushions, pillows and rolled towels where necessary
- Helping people cope with memory, concentration and sensory impairments
- Consider hand splints to prevent deformities and control pain. Involve a specialist splinting service or local orthotics department if required
- Promote quality of life through supporting engagement in meaningful activities
- Be honest about what can be offered and what can be achieved, particularly about time frames
- Consider the use of bed positioning systems or using cushions/pillows to maximize comfort in bed and prevent lower limb contractures.

OCCUPATIONAL THERAPY INTERVENTION

ADVANCED AND END STAGES OF LIFE

Both PSP & CBD are progressive conditions with limited life expectancy. A referral to the local specialist palliative care team (SPCT) should be initiated early on in the disease progression.

The SPCT's role is to support the individual and their carers from the point of diagnosis to end of life. This is likely to include the psychological and spiritual concerns of a progressive condition. They will also provide support with symptom control, facilitating discussion around advanced care planning and preferred priorities of care, liaison with local hospice care including respite, day therapy services and pre-bereavement support for the family.

There may be an OT in the SPCT who will be a good resource for managing functional ability at end of life and issues such as fatigue and anxiety management.

The SPCT can support discussions and processes around advanced decision making to ensure the individual's wishes are adhered to in relation to their care, active treatment and resuscitation status.

Probable difficulties in the advanced stages and towards the end of life

- Increasing immobility leading to increased stiffness, pain on movement and possible contractures
- Susceptibility to pressure sores
- Communication may be extremely difficult, adding to the individual's frustration. However, they often remain aware and alert of what is going on around them
- Double incontinence and urinary tract infections are common
- Cough reflex weakens, therefore chest infections and the risk of aspiration pneumonia increases
- Swallowing difficulties with a high risk of aspiration
- Recurrent infections
- Weight loss.

OT intervention should focus on the safe management of decreasing functional ability and reduced activity

- Supportive seating systems such as tilt-in-space wheelchair
- Equipment to assist with safe moving and handling such as a hoist
- Support with appropriate positioning and turning in bed
- Pressure care needs
- Maintaining meaningful activity
- Carer support and education
- Reminiscence work such as memory boxes
- Ensure personal care needs are effectively met in conjunction with other members of the team
- Where continuing healthcare funding is appropriate, provide supporting evidence for applications and reviews.

Collaborative working with the MDT is vital at this stage to ensure the individual and carers are supported with a consistent approach to meet their changing needs. A continuing care assessment and social care assessment are likely to be required to ensure appropriate support and funding is in place.

PSP & CBD have a major impact on the whole family, not just the individual. Living with a progressive disease changes the present and future life of their partner, close family and friends. Children, particularly those who are still living at home, are likely to be required to take on new and additional roles and they may have to adjust to the changing needs and behaviours of their parent. Relatives and friends assisting individuals with dementia-type symptoms often experience helplessness, frustration, anger, social isolation and the loss of autonomy.

As the disease progresses with increased physical deterioration and communication difficulties, carer stress can understandably increase and can be compounded by behavioural changes.

Research suggests that a goal-directed rehabilitation programme for individuals with mild to moderate dementia, including carer training, showed a significant improvement in the carer's sense of competence and improved daily function. The importance of the carer's role and stress should not be underestimated and should remain an integral part of all assessments.

Carers may benefit from education on the condition and access to resources and services to enable them to feel in control of their situation as much as possible.

PSPA is a valuable source of support for carers offering a helpline and information service and local groups.

Guidance for supporting carers

- Initiate early referrals to social care for a Carer's Assessment
- Discuss with the MDT an early referral to the palliative care team to provide carer support and advanced planning for end of life care
- Provide information about PSPA at the earliest opportunity
- Provide information on non-statutory support organisations such as Carers UK and the Carers Trust who may be able to provide additional support for carers
- Consider day care services if appropriate
- If possible, encourage the carer to access the local hospice for example alternative therapies, counselling services and carer groups

- Facilitate discussions about coping strategies and support available
- Consider telecare and personal alarm systems that may reduce the need for 24 hour supervision
- Ensure carers have the practical skills and appropriate equipment required to carry out tasks in a safe manner, which does not put them at risk (for example moving and handling). Complete referrals to specialist OT services or other MDT members where appropriate
- Provide information on entitlements to financial benefits and exemptions
- Ensure communication between carers and all team members is consistent, appropriate and accessible, using a key-worker system if appropriate
- Recognise that carers have often become experts in these conditions and its impact on those they care for, and positively collaborate with this as a strength
- Support individuals and carers in Lasting Power of Attorney applications where appropriate
- Encourage carers to continue to pursue their own interests and activities to maintain their well-being.

CONCLUSION

Individuals with PSP & CBD contend with an array of rapidly changing impairments affecting their ability to engage in daily activities within the home and the community. Each individual requires ongoing holistic OT assessment and intervention to address how these impairments are affecting them and their carers at the different stages of the disease process. OTs can effectively use their clinical reasoning and learnt knowledge of the conditions to work with people living with PSP & CBD, even if they have limited prior experience in this area.

We hope this booklet provides an understanding of the impairments associated with PSP & CBD and how they impact on all areas of daily living, along with practical tips for OTs to use during intervention. Although there is no specific research relating to OT and PSP or CBD, there are considerable resources supporting the role of OT in neurology and palliative care. These outline how OTs use their core skills to support people with the changing impact of their illness on daily life.

The evidence for this booklet has been drawn from expert opinion and experience and evidence from comparable progressive neurological conditions.

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REFERENCES

A reference list of the evidence to support this guide is available on request. Please make your request by email to helpline@pspassociation.org.uk

Or write to us at
Helpline and Information Services, PSPA, Margaret Powell House,
415a Midsummer Boulevard, Milton Keynes MK9 3BN

WE WELCOME YOUR VIEWS

PSPA encourages feedback about any aspect of the information we produce. Your feedback is really important to us, as it helps to develop new material and improve our existing information for the benefit of people living with PSP & CBD and those who care for them.

Please send your feedback to: helpline@pspassociation.org.uk

PSPA is the only national charity offering support and information to people living with PSP & CBD, while supporting research into treatments and ultimately a cure for these conditions.

PSPA offers:

- Support for people affected by PSP & CBD
- Provides information, educational resources and training opportunities for health and social care professionals
- Funds research into treatments and diagnostic tools.

PSPA Helpline and Information Service

Our Helpline and Information Service offers information and support on all aspects of PSP & CBD including symptom management, improving quality of life and signposting to other organisations.

Our telephone and email service is confidential and we aim to respond to all telephone enquires within 24 hours (during normal office hours) and email enquires within two working days. Our opening hours are Monday to Friday 9am - 9pm.

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

Information Resources

We provide high quality information resources for health and social care professionals who work with people living with PSP & CBD. We also have a wide range of resources for people affected by PSP & CBD.

Downloads of all our publications are available from our website or you can order directly from the helpline.

PSPA Support Groups

Many of our volunteer-led groups invite visiting speakers such as benefits advisers and health and social care professionals, to share their expertise on managing PSP & CBD on a daily basis.

If you would like more information on our local support groups, please contact our helpline or visit our website. www.pspassociation.org.uk

Regional Support and Information

Our regional teams work to ensure that people affected by PSP & CBD have access to good local support. They are on hand to help local health and social care providers gain a greater understanding of the care needs of people and to ensure that services meet agreed standards of care. They also focus on raising the profile on both conditions by informing, influencing and educating through delivery of regional training and educational events.

Our website

Our website offers accurate, timely, and relevant information on all aspects of PSP & CBD, including the latest news on research and events. www.pspassociation.org.uk

PSPA forum

Our forum HealthUnlocked is a safe place for people affected by PSP & CBD to share experiences and support each other with the challenges living with the conditions.

Our forum can be accessed via www.healthunlocked.com/psp

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