

NHS CONTINUING HEALTHCARE (CHC)

GUIDANCE NOTES FOR HEALTH AND SOCIAL CARE PROFESSIONALS

As Health and Social Care Professionals, you may be required to carry out CHC funding assessments for people living with Progressive Supranuclear Palsy (PSP), or provide evidence to support an application. PSP is a rare condition, so this information sheet has been devised to provide guidance to members of the health and social care team involved in the CHC assessment process.

**INFORMATION *STARTS*
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What is PSP?

PSP is a rare, progressive neurological condition which affects areas of the brain stem and basal ganglia. It significantly affects speech, swallow, vision, mobility and cognitive processes. PSP is complex and individual in the way it develops and each person experiences different symptoms, in different orders and with varying severities. Deterioration in functional ability can be rapid and unpredictable. Symptoms can fluctuate from day to day or hour to hour, causing unpredictability throughout the progression. Poor balance, coupled with a lack of insight into changing physical abilities can lead to a high risk of falls early on in the condition, with risk of head and other injuries.

As the condition progresses urinary tract infections (UTIs) and chest infections/ aspiration pneumonia become more frequent and severe. Average life expectancy from onset of symptoms is 5-7 years but it may take several years to be diagnosed. There is no cure for PSP and management focuses on the palliation of symptoms and quality of life.

What to look for when assessing for CHC

- The complex nature of the symptoms of PSP is not always immediately apparent, so knowing what to look for is vital to ensure that sufficient evidence is provided for all CHC applications
- Highlight the hidden symptoms and complexities of PSP, such as the difficulties with risk taking
- An up-to-date assessment from all relevant professionals is central to the CHC process. Check to ensure that your client is being seen by all relevant members of the multidisciplinary team (MDT)
- Evidence is key. It is important to build a full picture of your patient's/client's condition, and the effect PSP has on their life. Be descriptive and explicit about what is happening, and how it affects the individual. Explain what care or input is required to overcome the issues, and its frequency. Also note how symptoms impact on each other, and where symptoms overlap and cross over more than one domain, enter it in each section. Whilst symptoms won't be scored twice, it will give an indication of the nature, complexity, intensity and unpredictability of the need
- Family carers may underestimate the complexity of the care they provide and how much they have to do for the person with PSP. Encourage them to keep a diary of the care and supervision they provide on a daily basis, as the evidence gained will highlight the intensity
- Remember, well-managed needs are still needs. Consider whether the need would be met if the management techniques put in place were withdrawn. Record at the level of need that would be present if the ongoing intervention was withdrawn.

A guide to PSP and the 12 domains of CHC

Below are the 12 care domains of CHC, with many of the potential symptoms and effects of PSP listed within the relevant areas. This is not an exhaustive list and is intended to be used as an aid when completing CHC applications. It is not a replacement for a full and individual assessment. The impact of PSP on each person is variable but the condition is always progressive and frequently unpredictable. For fluctuating symptoms describe the most disabling level, and record duration and frequency. You may need to emphasise that as fluctuations are often unpredictable they require constant or frequent monitoring/support to ensure care needs are met appropriately.

Behaviour

- May exhibit challenging or unexpected behaviours and/or mood changes (eg aggression, frustration, depression) – requiring specialist advice/handling or medication
- May be resistant to care and treatment
- Impulsivity and/or apathy can have a major effect on all aspects of care
- Other impulsive behaviours can include cramming foods/gulping drinks, which can significantly increase risk of choking/aspiration where swallowing problems also exist (see *nutrition section*)
- There may be a lack of inhibition leading to ‘socially unacceptable’ behaviour
- There may be withdrawal from attempts to engage in planning, support or activities of daily living
- There may be fixed and rigid thinking which may reduce co-operation, making aspects of care difficult
- There can be major sleep disturbance, with difficulty falling asleep or remaining asleep. Unsafe behaviour, such as getting out of bed unaided, may take place at this time, leading to falls and injury
- There may be emotional blunting, a lack of empathy and fixed or obsessional thoughts. This may be very demanding of carers without them realising. Be aware of caregiver distress
- Is the mental health team involved?
- Mood disturbances are common including depression. If there are concerns about depression, referral to the GP or a psychiatrist is advisable
- Use evidence from risk assessments if available.

Cognition

- Executive functioning skills can be significantly affected – slowness of thought, difficulty with recall, mental capacity issues, disorientation and word finding/ language difficulties have substantial effects on the individual's abilities and quality of life
- Slowness of thought can substantially reduce ability to communicate
- Needs often have to be anticipated by those around the patient. Support, encouragement and prompting with all aspects of daily living and managing care is often required and without this support there is significant risk of neglect
- Often unable to assess basic risks/are dependent on others to stay safe. Consider the degree of risk to the individual in relation to cognitive ability
- Ability to follow instructions may be significantly slowed, increasing time required to carry out everyday tasks. May be unable to follow instructions/respond appropriately
- Mental Capacity: may appear to have Mental Capacity, but this may be questionable due to lack of insight into danger
- Capacity to make decisions is often impaired or lost – a high level of communication skills is required by carers. If care or treatment arrangements amount to a deprivation of the person's liberty, then consideration must be given to whether Deprivation of Liberty Safeguards (DoLS), applicable to hospital or care home or Deprivation of Liberty in a Domestic Setting (DIDS) needs to be in place
- Use evidence from risk assessments where appropriate.

Psychological/Emotional

- Mood changes including anxiety, depression, frustration, aggression and hallucinations may have an increasing impact on quality of life. Counselling support or review by mental health team may be indicated
- Cognitive and emotional changes may make dealing with diagnosis and prognosis difficult, which can make planning ahead more difficult
- Difficulties in sleeping/staying asleep can cause very disturbed nights (increased risk of falls in the night) requiring constant supervision or support
- Extreme fatigue and apathy are common and can negatively impact on ability to carry out everyday tasks and leisure activities/hobbies
- Emotional lability behaviours may be inappropriate to the situation, with excessive laughing or crying
- Lack of facial expression, slurred or very quiet speech and physical immobility can make it hard to tell how the person with PSP is thinking and feeling, requiring skilled carers to ensure appropriate support

- Difficulties recognising the emotions of others can create tension between people living with PSP and those caring for them. Person living with PSP may not recognise this and be confused or upset by the reactions of others
- Use evidence from risk assessments where available.

Communication

- Communication may be severely impaired by slowness of thought and apathy. There may be reduced comprehension and understanding of language. Word finding is often affected
- Speech: there may be palilalia (stuttering), slurred speech, and/or hypophonia (quiet speech) which hinders communication. In addition there may be echolalia (for example, repeating a word or phrase that someone has said to them, rather than responding to what has been said)
- Learning new skills is difficult
- Response to closed questions can be confused (even when using yes/no signs or gestures)
- Care needs may need to be anticipated by those who know the person well if there is difficulty in reliably communicating
- People living with PSP may say they feel well, even when they do not (sometimes even at end of life stage). They may experience physical pain and/or emotional distress but may have difficulty communicating this directly. Emotional pain may be communicated as behavioural disturbance. Careful and skilled observations are required at all times to ensure that they are comfortable and symptoms are under control
- Reduced eye movements affect ability to read and make eye contact
- Eyelids may close involuntarily (blepharospasm) and may not open again for long periods of time (apraxia of eyelid opening), reducing social interaction further
- Mobility issues, restricted eye movement and cognitive issues may limit communication aid options
- Communication can take considerable time and require skilled carers. As the condition progresses nonverbal cues reduce and all communication is through familiarity.

Mobility

- Slowness of movement (bradykinesia), severe axial rigidity (stiffness in the trunk and neck), postural changes, poor balance and a lack of 'righting reactions' all increase risk of falls. Falls are frequently backwards, and often sudden
- Limited insight into reduced abilities and risks, along with motor recklessness and impulsivity leads to a very high risk of falls. For many, constant supervision will be required to maintain safety

- May try to mobilise suddenly without support. This can happen frequently and unpredictably so constant supervision is often required
- High risk of falls must be evidenced in the care plan, and any falls/injuries/fractures and near misses should be recorded. Encourage family carers to keep a diary
- May be unable to get up after a fall. May not call for help after a fall due to cognitive and/or communication issues. This is a particular risk if living alone but is also still true for people living with others or even in care homes, so regular monitoring by carer or care staff is important
- As the condition progresses, falls often increase in frequency, and may require constant supervision to maintain safety
- Restricted eye movement and inability to look down increases risks of falls when mobilising.
- Trip hazards may not be seen. Inability to look down also makes using the stairs extremely unsafe. Environment needs to be monitored to reduce risk of trips and falls
- Cognitive issues can make it harder for people with PSP to learn how to safely use mobility equipment such as walking frames
- Later on may be unable to walk, or be confined to bed for long periods
- Specialist seating/wheelchair may be required
- Ongoing physio/OT input as condition progresses. May require support with exercise regimes or passive exercises as well as ongoing support with moving and handling, equipment and adaptations.

Nutrition

- The majority of people living with PSP will experience dysphagia (swallowing problems). Swallowing deteriorates over time and the risk of aspirating and choking will be high. Ongoing assessment/review by the speech and language therapist (SLT) and dietitian is essential to avoid malnutrition, aspiration and choking. Supervision especially when feeding is required to ensure safety
- Keep a log of all choking incidents and referrals to SLT
- Supervision and limitation of distractions may be required where cognitive or behavioural challenges indicate that person may be at increased risk of choking (ie from cramming food or eating/drinking too fast)
- Those with poor swallowing may have trouble following medical advice to modify consistency or thicken drinks
- Physical limitations such as postural changes, muscle rigidity and deterioration in functional ability will have an impact on the ability to eat and drink and the person with PSP may require assistance with feeding and positioning

- Record time taken to eat a meal, especially where this exceeds 30 minutes
- Calorie intake can be significantly reduced. Please take the Malnutrition Universal Screening Tool (MUST) score into consideration
- Record weight loss
- Most people living with PSP will need to consider use of Percutaneous Endoscopic Gastrostomy (PEG) at some stage. Early discussions are advised due to potential for mental capacity, and communication, to be lost
- PEG can be problematic for some, and this should be recorded in the assessment
- Excess saliva can cause significant discomfort and management issues, and there will be a risk of aspiration from this even in cases where a PEG tube is fitted
- If PEG is refused by the person with PSP, or is not medically appropriate, consideration must be given to the palliation of symptoms and quality of life. Support from skilled carers may be required if patient is 'fed at risk'.

Continence

- There can be symptoms of overactive bladder – frequency/urgency and nocturia
- There can be hesitancy in passing urine or incomplete bladder emptying
- Incidence of UTIs increase as the condition progresses requiring monitoring and treatment
- There may be poor fluid intake as a result of swallowing and cognitive difficulties which increases risk of UTIs and bladder irritability
- Incontinence management and support from a continence adviser may be required. Management plan will need to consider an individual's cognitive abilities when deciding style of management
- Constipation can be a significant issue and often requires aperients. May require skilled intervention beyond normal bowel care, for example, enemas or suppositories
- Sleep may be frequently disturbed by nocturia, increasing risk of falls during the night. Visits to the toilet can be excessive both day and night and need to be noted.

Skin Integrity

- Skin requires regular checking through the day and night if unable to move limbs independently or walk. Increased risk of breakdown
- Include Waterlow Score, which gives an estimated risk for the development of a pressure sore in a given patient
- Repetitive actions can lead to skin breakdown
- Record wounds relating to injuries as a result of motor recklessness

- For some, hand contractures that lead to difficulty maintaining hand hygiene, can result in skin breakdown
- Record referrals to Tissue Viability Nurse where skin breakdown is not responding to treatment and requires specialist dressings
- Cognitive issues may reduce compliance with use of pressure relieving aids and care regimes.

Breathing

- There can be a high risk of chest infections/pneumonia due to aspirating on food/drinks/saliva which require antibiotic therapy – may require hospitalisation (depending on the person's wishes). Infections can cause a sudden deterioration in symptoms including hallucinations/delirium requiring skilled monitoring and care
- Record number of chest infections
- Oral secretions can be excessive and difficult to control. Medications and/or oral suctioning may be needed
- Referral to a respiratory specialist may be required
- Input from a physiotherapist may be required to advise on chest clearing techniques.

Medication and Symptom Control

- Many symptoms may require medication management on a regular or PRN basis, such as anxiety, agitation, pain, constipation, management of excess saliva etc
- Fluctuations in condition are likely. Medication may need to be managed by skilled carers able to monitor efficacy and make decisions to provide further medications on a PRN basis as prescribed, and to observe for side effects
- Reduced blink rate can cause dry/sore eyes, requiring eye drops/ointments to relieve and protect the eye from damage
- Carers/family need to be able to recognise and report on signs of chest infections/ pneumonia or UTIs, which increase in frequency as the condition progresses and will require treatment (as per person's individual wishes regarding treatments). Infections can cause sudden deterioration requiring fast intervention to minimise impact
- People living with PSP may not show the common signs of infection. For example, they may not have a raised temperature, may not cough or have a change in going to the toilet. If there is a rapid deterioration over a few days then infection should be considered and tested for, usually by the GP
- There may be non-concordance or non-compliance with medications due to cognitive impairment.

Altered States of Consciousness

- Dependent upon stage of the condition. Increasing periods of sleeping or drowsiness as condition progresses
- Significantly reduced blink rate and involuntary eyelid closure can make it appear that someone is asleep when they are not
- Apathy and depression can be severe and reduce responsiveness
- Comorbidities may impact of consciousness.

Other Significant Care Needs

- This domain needs to include any area not covered by the other 11 domains. This may include the quality of interactions, quantity and degree of current support, how needs present and the skills needed to manage them
- Fluctuations and instability and/or rapid deterioration in the condition on a daily basis
- May include management of fatigue, pain and co-existing conditions
- Often requires skilled emotional support for prognosis and Advanced Care Planning which should be considered early before cognitive and communication difficulties interfere. Involvement of Palliative care team where possible.

Overall Considerations

- Cognitive issues can affect any of the 12 domains, making care more complex
- PSP is a progressive condition - the course of the condition can be very unpredictable and problems will increase
- Constant supervision and/or support may be required 24 hours a day
- A high level of MDT input and coordination is required
- It is important to gain multiple perspectives. We recommend that all key MDT members input into the CHC assessment process. This may include, but is not limited to Neurologists, Physiotherapy, Occupational Therapy, Speech and Language Therapy, Dietitian, Parkinson's Disease Nurse Specialist, Palliative Care, Community Nurses, Social Worker, Psychologists or other members of the mental health team. The National Framework recommends that the MDT should comprise a team of at least 2 professionals, from both health and social care disciplines
- Consider input from care staff/activity coordinators, who may also be able to offer insight into how the person is on a day-to-day basis
- A statement from family carers can be a powerful tool
- Palliative care services usually have a key role from an early stage in supporting the individual to maintain quality of life, whilst also supporting family carers.

Useful contacts

PSPA Helpline and Information Service
Tel: 0300 0110 122
helpline@pspassociation.org.uk
www.pspassociation.org.uk

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