

The role of the Parkinsons nurse with symptom control in PSP and CBD

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- ▶ **Debbie Thurman**; clinics Cheltenham and Cirencester
 - ▶ Home visits Cirencester/Lechlade/Dursley/Wotton

- ▶ **Emma Sodzi**; clinics Stroud and Gloucester
 - ▶ Home visits Stroud and Gloucester

- ▶ **Ellen Bennett**; clinics North cots and Gloucester and Tewkesbury
 - ▶ Home visits North cots, Tewkesbury and Cheltenham

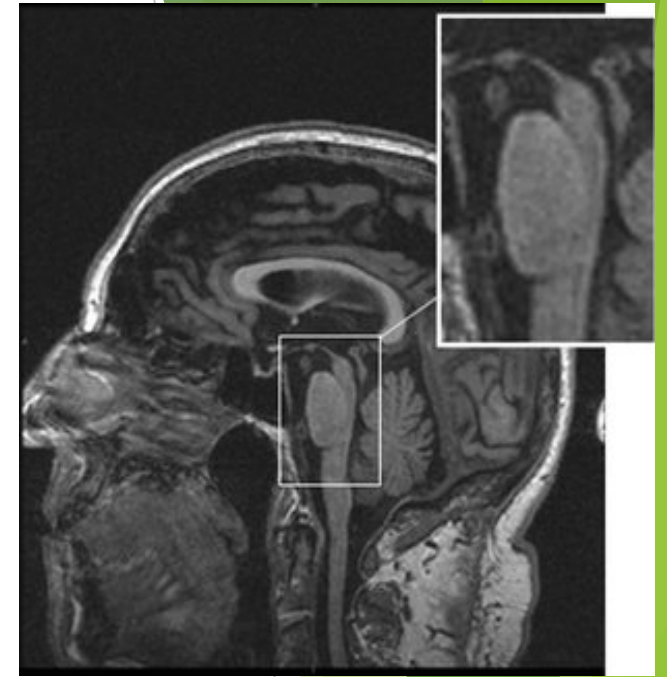
- ▶ **Jackie Burnett**; clinics Forest of Dean and Stroud
 - ▶ Forest of Dean/Stroud /Dursley

How is PSP and CDB diagnosed ?

- ▶ Consultants make the diagnosis
- ▶ Look at reflexes, stiffness in muscle groups and weakness
- ▶ MRI to rule out other pathologies and hummingbird sign in PSP
- ▶ DaTSCAN - doesn't differentiate between different types of Parkinsons
- ▶ Radioactive tracer, injected into the blood, goes into the brain. Attaches to dopamine transporters

PSP and CBD

- ▶ Difficult to diagnose - subtle at first, affects walking, impairing balance
- ▶ Decreased blink rate
- ▶ Small handwriting, decreases in size as the writing continues
- ▶ Small, movements of the hands and the feet,
- ▶ Characteristic stiffness of the arms and the legs
- ▶ Often started on Parkinsons medication but no improvement



How is PSP and CBD diagnosed?

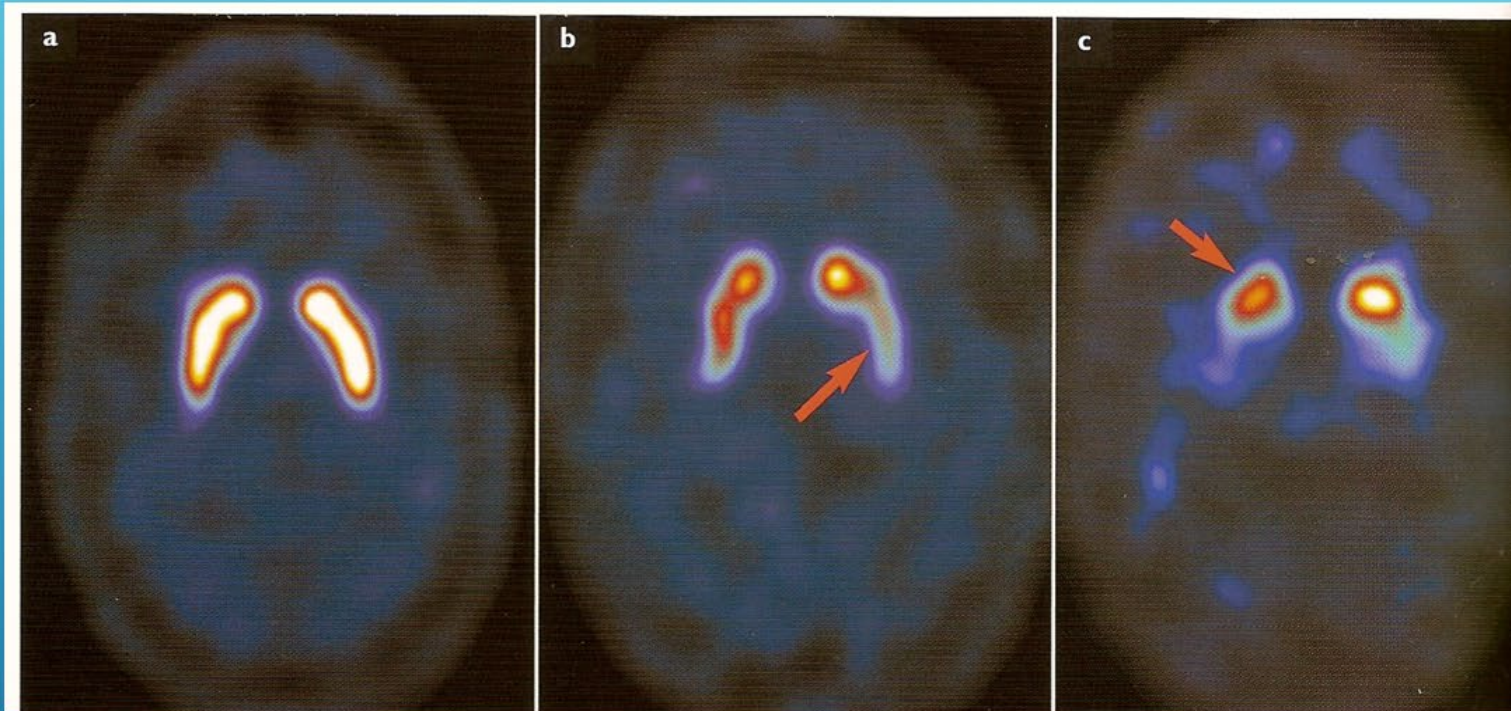
PSP

- ▶ Effects muscles controlling eyes -difficult to focus
- ▶ Unlike Parkinsons people lean backwards and fall backwards
- ▶ Slurred Speech and swallowing - difficulties early

CBD

- ▶ Tremors and jerky movements
- ▶ Impaired balance and co ordination
- ▶ Alien hand - one hand moving on its own not under conscious control
- ▶ Apraxia- difficulty performing familiar movements using utensils or clothes

DaTSCAN



Comma shaped
caudate and putamen
on DaTSCAN

Pattern seen in healthy
individuals and also in ET

Reduction (L>R) in
putamen but bilaterally
abnormal

Patient had 2yrs symptoms,
with greater problems on
right side of body

Advanced case

Almost no activity in
putamen and
bilaterally reduced in
caudate

PSP common symptoms

- ▶ Stiffness/rigidity and slowness of movement
- ▶ Balance problems
- ▶ Trouble controlling upward and downward eye movements
- ▶ Behavioural changes - unexpected emotions (crying or laughing)
- ▶ Tremors in the hands
- ▶ Blurred vision
- ▶ Slurred speech and trouble swallowing - more affected than idiopathic Parkinsons
- ▶ Depression
- ▶ Difficulty controlling eyelids, unwanted blinking or unable to open eyes
- ▶ Saliva management

CBD common symptoms

- ▶ Tremors and jerky movements
- ▶ Impaired balance and co ordination
- ▶ Alien hand - one hand moving on its own, not under conscious control
- ▶ Apraxia- difficulty performing familiar movements using utensils or buttons on clothes
- ▶ Often one limb will become particularly flexed /stiff/spasticity
- ▶ Dementia memory problems and changes in language skills
- ▶ Swallowing problems can lead to aspiration
- ▶ Personality changes apathy, irritability, anxiety,
- ▶ Sensory loss -difficultly identifying things by touch
- ▶ fatigue

Stiffness/rigidity and slowness of movement

- ▶ There are 5 different types of PSP
- ▶ One type responds to medication used to treat Parkinsons and helps with slowness and stiffness
- ▶ Use levodopa medications e.g. madopar and Sinemet
- ▶ If swallowing problematic tablets can be crushed or dispersible medication used or rotigotine patch (absorbed through the skin)
- ▶ Stretches and physiotherapy can be helpful with rigidity

Pain - rigidity/spasticity and MSK issues

- ▶ **If pain is a symptom - what is the cause?**
 - ▶ Common MSK issues e.g. hip, knee pain or rotator cuff tear
 - ▶ Needs discussion with GP so appropriate x rays, pain relief, referrals to physiotherapists or orthopaedics -
 - ▶ If Osteoarthritis (OA) wear and tear- paracetamol helpful
 - ▶ With back issues pain could be neuropathic (irritated nerve)- described as burning or toothache ; gabapentin and pregabalin can be helpful
- ▶ **If rigidity/spasticity is the cause**
 - ▶ Gentle stretches, warmth
 - ▶ Medications such as baclofen, gabapentin, dantrolene (used for spasticity)

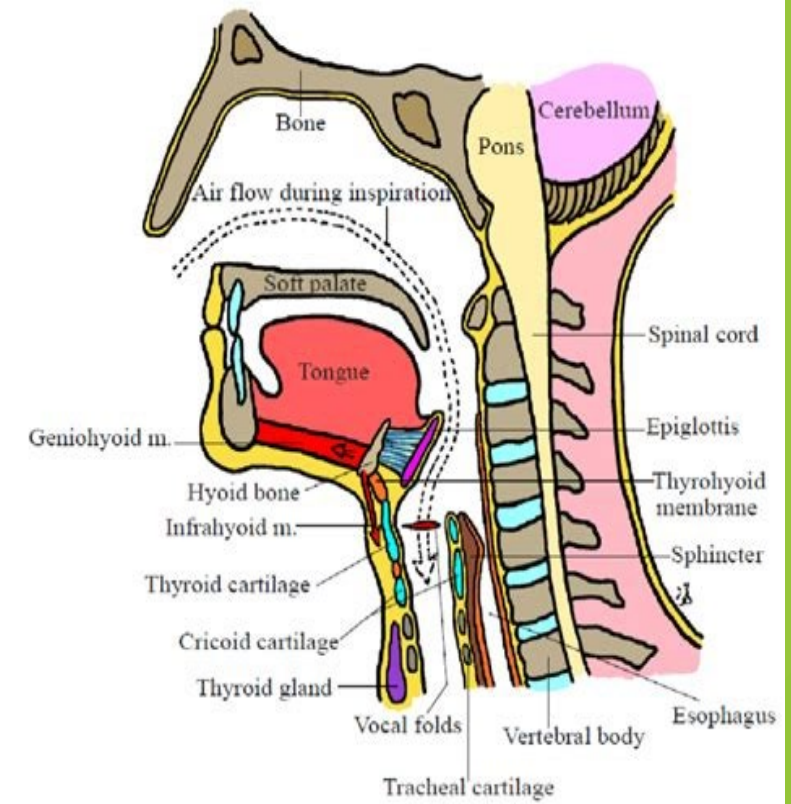
Behavioural changes

- ▶ Crying and laughing - emotionally liable
- ▶ Medication prescribed at GRH - dextromethorphan and quinidine combination
- ▶ Processing can become slowed and cognitive problems
- ▶ Depression and low mood
- ▶ Often prescribe mirtazapine
- ▶ **Referrals to**
- ▶ Longfield hospice and Leckhampton
- ▶ Clinical psychology at GRH
- ▶ Lets talk Gloucestershire self referral- 0800 0732200
- ▶ Later life mental health team
- ▶ Memory clinic

Swallowing

Advice

- ▶ Smaller mouthfuls
- ▶ Don't look down or turn the head to watch TV
- ▶ Softer foods
- ▶ Add sauces to make food easier to swallow
- ▶ Dry foods are particularly difficult
- ▶ Referral to speech therapy team - give further advice and assess swallowing
- ▶ PEG - tube into the tummy for food if losing weight

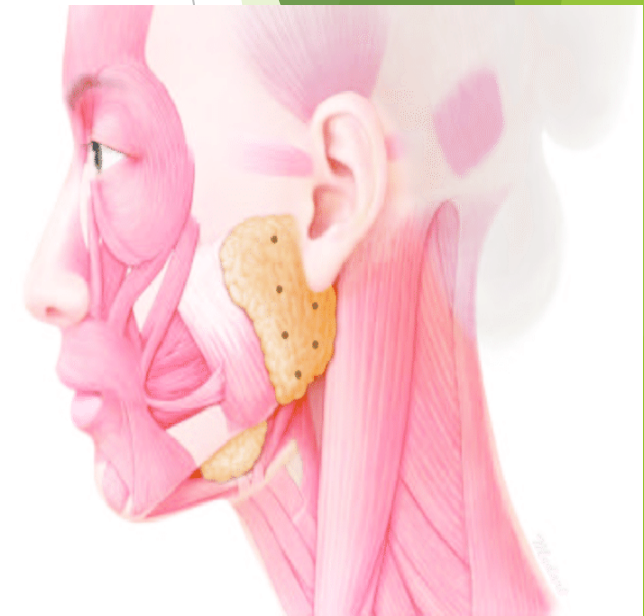


Speech

- ▶ Areas of the brain controlling the movement of the tongue, lips and throat can impact on speech making it slurred and difficult to understand
- ▶ Can become slow, slurred or very quiet.
- ▶ Speech therapists can give exercises to practice
- ▶ May want to bank your voice with speak unique
- ▶ Assisted devices - Bristol
- ▶ Apps on I pads - grants available for some equipment

Saliva management

- ▶ Same amount of saliva is produced reduced automatic swallowing reflex
- ▶ Swallowing reflex produces activation of the tongue, pharyngeal and laryngeal muscles to propel the food bolus/saliva from oral cavity to oesophagus without aspiration of food into the airway.
- ▶ Watch which buzzes to encourage swallowing
- ▶ App on mobile as a reminder
- ▶ Sucking sweets to stimulate the swallow
- ▶ Can wear neckerchief
- ▶ Botox injections - every 12 to 16 weeks at Gloucester Royal into parotid gland
- ▶ Medications include glycopyrronium tablets and liquid and atropine eye drops
- ▶ Botox clinic at Gloucester Royal on Fridays



Vision

- ▶ May experience visual problems which can't be corrected by glasses
- ▶ Double vision
- ▶ Tunnel vision - where the field of vision is reduced
- ▶ Blurred or misty vision
- ▶ Slow jerky eye movements
- ▶ Difficulty looking up or down
- ▶ Bright light sometimes problematic and more comfortable with shades
- ▶ Prism glasses can help to focus the eyes- double vision.

Constipation and bladder urgency

- ▶ Constipation due to lack of mobility and progression of disease
- ▶ Encourage a balanced diet fruit and vegetables
- ▶ Soups to maintain fluids
- ▶ Laxatives such as laxido and bisacodyl may be needed

- ▶ Bladder urgency - remove stimulants e.g. caffeine, fizzy drinks and alcohol. Concentrated urine will irritate the bladder so plenty of fluids
- ▶ Medication such as mirabegron helpful to dampen messages from brain of urgency
- ▶ A continence team referral may be helpful.
- ▶ Pads can be ordered on NHS

Thankyou

Any questions?

Making the most of Appointments

Write down any questions to help prompt

Main issues 2/3 things to discuss