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## The Parkinson's Journey

From diagnosis to death and what lies between

Not going to talk about drug treatments in any detail



## What is Parkinson's ?

Progressive and fluctuating neurological condition that primarily affects movement

First described in 1817 by James Parkinson in his famous monograph *An essay on the shaking palsy*

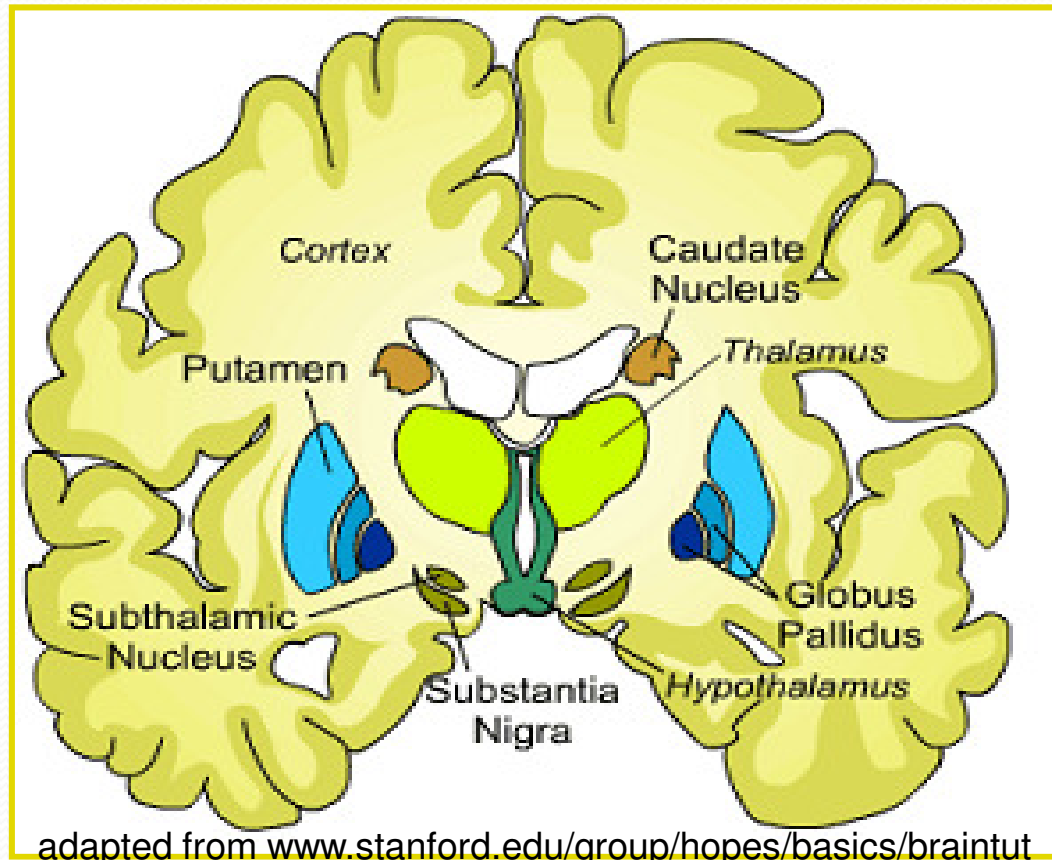


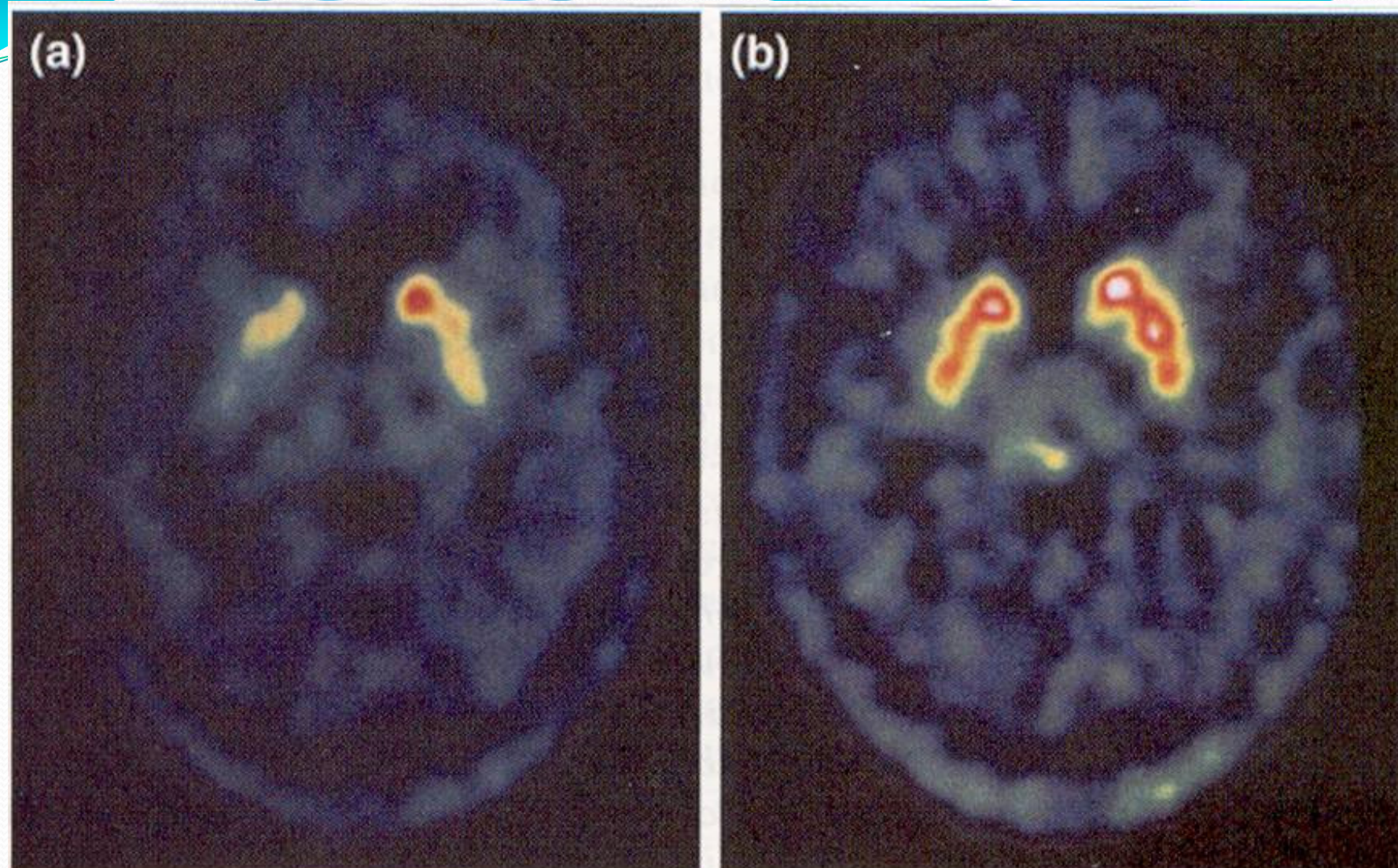
## What is Parkinson's Cont

It is a depletion and an imbalance of neurotransmitters

Now recognised that it is not simply a movement disorder, but a multisystem neurological disorder which affects cognitive processes, emotion and autonomic function

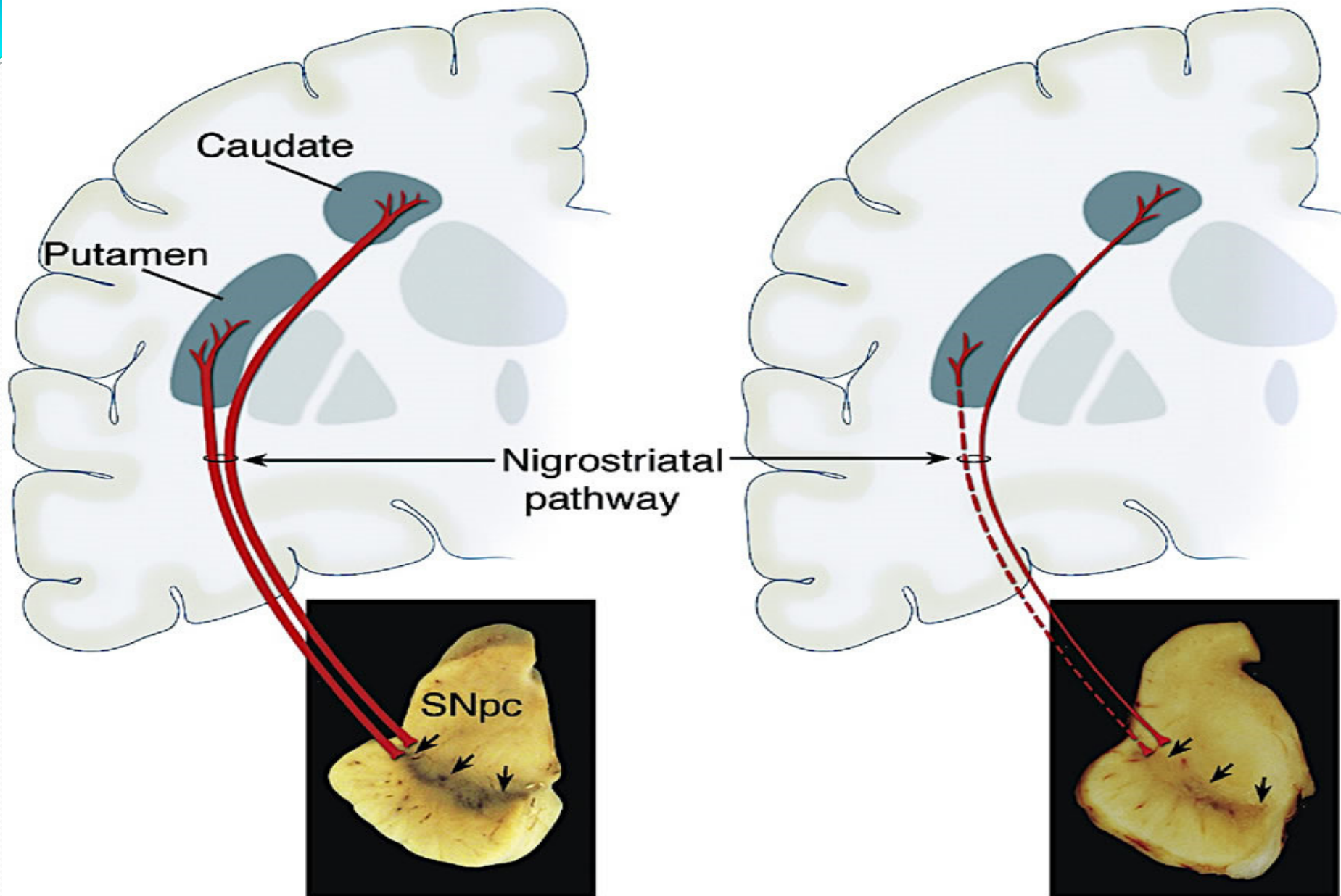
# Basal Ganglia structure





## Normal

## Parkinson disease



# Excess Acetylcholine

**Balance between dopamine and glutamate/acetylcholine**



Glutamate  
Acetylcholine

Dopamine

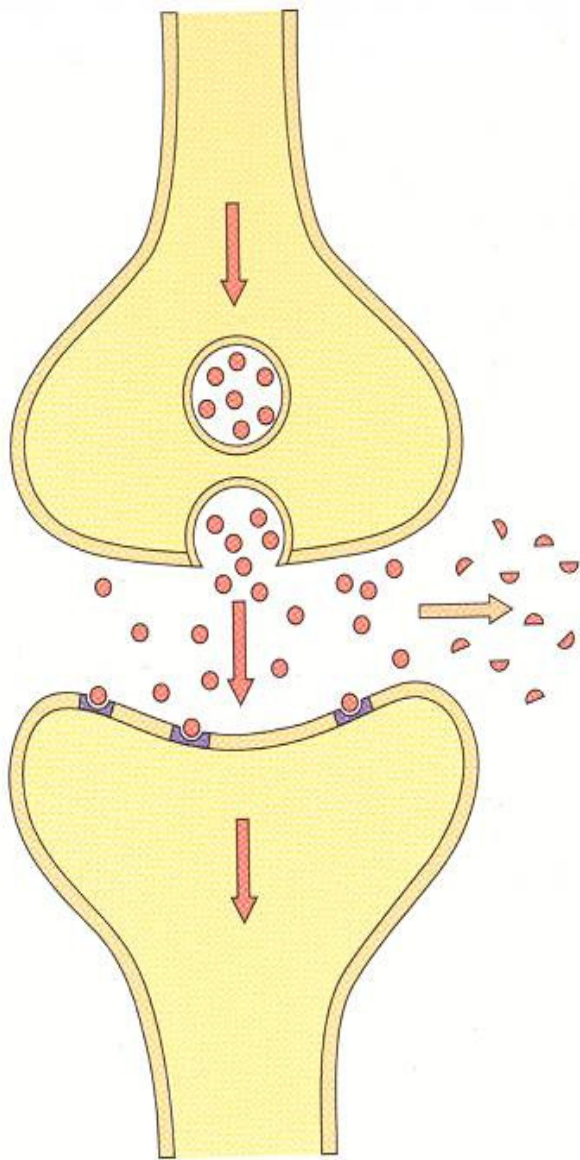
**Imbalance as a result of dopamine deficiency**



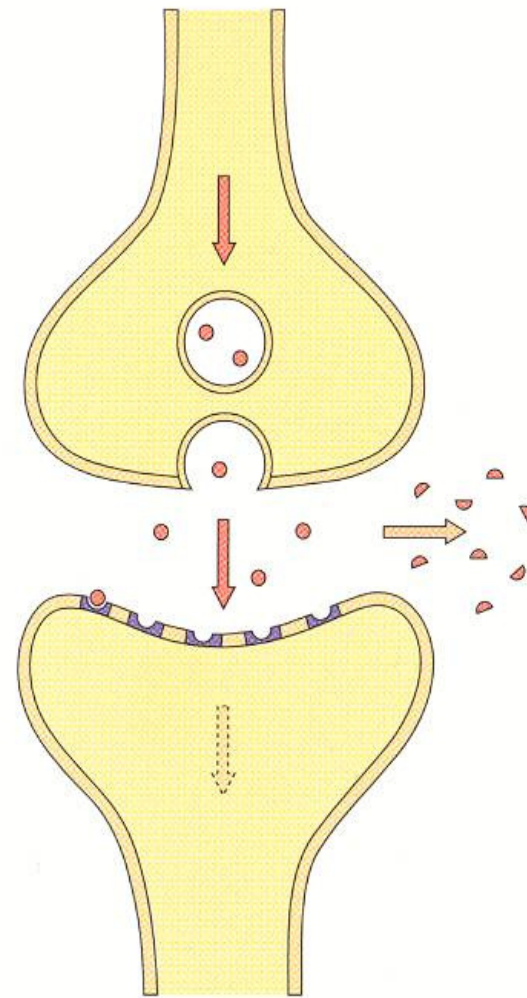
Glutamate  
Acetylcholine

Dopamine





## Hypoactive neurone



# Basal Ganglia simplified functions!

- \* Controls the preparation, initiation, sequencing and timing of well learnt motor skills
- \* 'auto pilot' facility
- \* Walking, swimming, senses ,influences position ( balance and posture when standing or sitting)

## What causes it?

- The aetiology of PD is unknown but factors such as aging, environmental insult and genetics have all been implicated.
- The neuropathology of PD is primarily related to degeneration of nigro striatal neurons associated with Lewy body pathology and a deficiency of dopamine in the substantia nigra

# Diagnosis

- Clinical
- No specific blood test to help
- Scanning can be helpful
- Misdiagnosis can be as high at 30-40%
- Specialist clinics have less of a misdiagnosis rate

## Cardinal signs

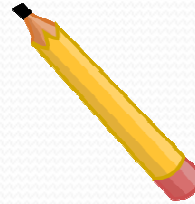
- Bradykinesia (slowness)
- 
- Rigidity (stiffness)
- Tremor (rhythmic shaking) at rest arm, leg, hand
- Two of these needed for diagnosis

# Other features

Hypomimia



Microphagia



Impaired blinking



**Monotonous Speech**, Reduction in speech volume,  
Dysphasia, **Swallowing**



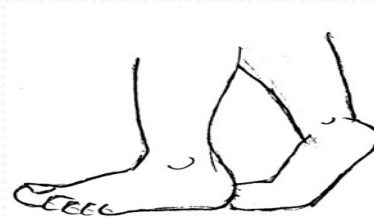
Autonomic Features ( B/P)  
Bladder / bowel  
problems



Sleep disturbance



Gait abnormalities



Neuropsychiatric  
Complications  
Depression

**Rigidity of thought**



# Other features

Hypomimia	Microphagia	Impaired blinking
Monotonous Speech	Reduction in speech volume	Autonomic Features ( B/P)
Dysphagia	Gait abnormalities	Neuropsychiatric Complications Depression
Sleep disturbance	Rigidity of thought	Bladder / bowel problems

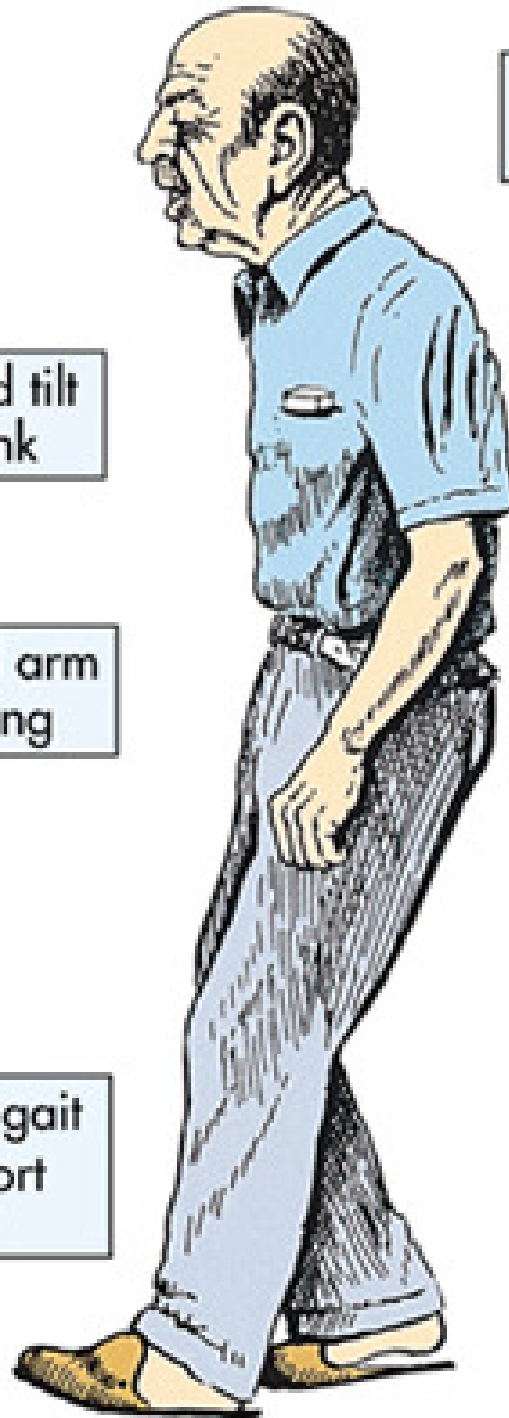
## Pt reported symptoms

- I find difficulty rising from an armchair, getting into and out of bed, and into and especially out of a car
- My memory is not good, I even forgot how to tie a tie
- I seem to take twice as long to dress and undress
- I find it difficult to fasten buttons etc.
- My voice is not as strong as it used to be



## continued

- My golf shots are now much shorter than they once were
- Sometimes when I am about to walk off from a standing start, my legs shake and I shuffle along for 2/3 paces before walking normally
- In general I now seem to take longer to do everything
- Thankfully I do not suffer any pain



Rigidity and  
trembling of head

Forward tilt  
of trunk

Reduced arm  
swinging

Shuffling gait  
with short  
steps

Rigidity and  
trembling of  
extremities



## Non-Motor Features of Parkinson's Disease

- Cognitive deficiencies
- Depression
- Raised anxiety levels
- Olfactory deficiencies (smell and taste)
- Sleep disturbance
- Fatigue
- Pain
- Bowel and bladder problems
- Sexual dysfunction



## Clinical management

- Diagnosis and treatment initiation
- Stable and maintenance
- Complex
- Palliative stage

# Development / Progression

## Before diagnosis - Stages 1 & 2

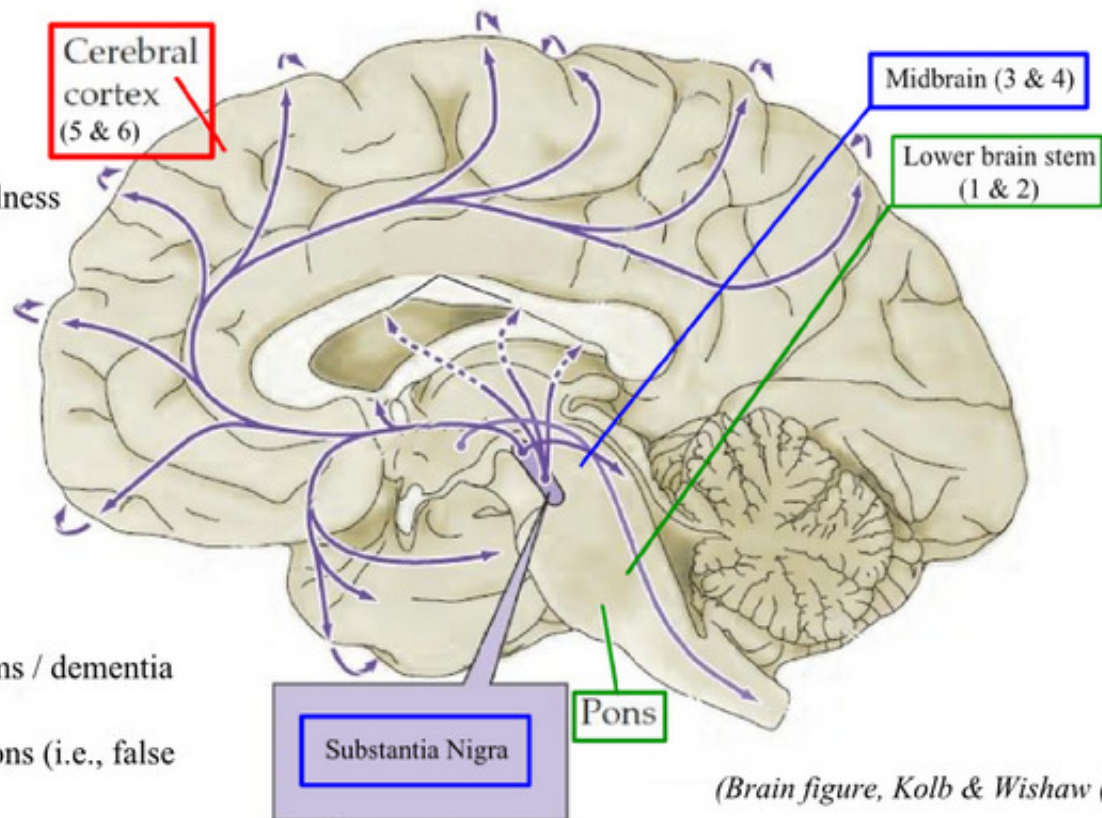
- loss of smell
- disturbance of sleep and wakefulness
- lowered blood pressure
- constipation
- anxiety / depression

## At diagnosis - Stages 3 & 4

- movement problems
- subtle thinking problems

## Later disease - Stages 5 & 6

- worsening movement problems
- more significant thinking problems / dementia
- worsening anxiety / depression
- hallucinations / paranoia / delusions (i.e., false beliefs)



(Brain figure, Kolb & Wishaw (2003))

# Parkinsonism

- Clinical syndrome involving bradykinesia plus one of the following features
  - Tremor – pill rolling at rest
  - Rigidity
  - Postural instability
- 
- You can have Parkinsonism without having Parkinsons disease

# Symptoms Progression

- Development of freezing during a motor function
- Dyskinesias known in patient literature as involuntary movement.



## Hallucinations/psychosis

- Can happen to any patient on dopaminergic treatment
- More likely if cognitively impaired
- More likely if depression, visual impairment or intercurrent illness





## Palliative care for non-cancer patients

‘Palliative care is currently provided mainly for people suffering from cancer, but it is increasingly recognised that people with a range of life threatening diseases may also benefit from it’

**(Scottish Office Management Executive Letter 1994)**



## Other management options

- Ensure that patients are referred to multidisciplinary team as early in disease as possible to ensure follow up over disease progression.
- Prevention of complications is better than cure.



## Nursing and other issues

- Timing of medication is very important
- Patients performance can vary according to time drugs are taken.

A yellow sticky note with handwritten text in black ink. The text is written in a cursive style and is underlined.

get it  
on time

To stop Parkinson's from getting out of control, people with Parkinson's need their medication **on time—every time.**

# Palliative stage in PD – definition


## NICE consultation

- Inability to tolerate adequate dopaminergic therapy
- Unsuitable for surgery
- Advanced comorbidity



## ***Palliative Care***

- *Palliative care in PD is the active total care of patients with advanced Parkinson's disease who no longer respond well to disease-specific symptomatic treatment. Control of pain, of other symptoms and help with psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.*
- ***Many aspects of palliative care are also applicable earlier in the course of the illness.***

- 
- “There is convincing evidence that many patients who die from non-malignant disease have unmet need for symptom control, psychosocial support, open communication, control over their final days and choice about the care they receive. These patients and their informal carers, facing considerable distress in the final months of life, need palliative care. For many, adoption of the palliative care approach to their care will be adequate. For others, with complex needs, specialist palliative care will be appropriate.”
  - **"Reaching Out: Specialist Palliative Care for Adults with Non-Malignant Diseases" (1998) National Council for Hospice and Specialist Palliative Care Services**



## ***Palliative care:***

- *Affirms life and regards dying as a normal process*
- *Provides relief from pain and other symptoms*
- *Integrates the psychological and spiritual aspects of patient care*
- *Offers a support system to help patients live as actively as possible until death*
- *Offers a support system to help the family cope during the patient's illness and in their own environment*



## Defining palliative care

- *‘Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’*

**WHO 2005**

**Living and Dying Well (2008)**

# PD Management

- Complex
- Drug issues
- Health
- Address problems as they occur
- Palliative care ????



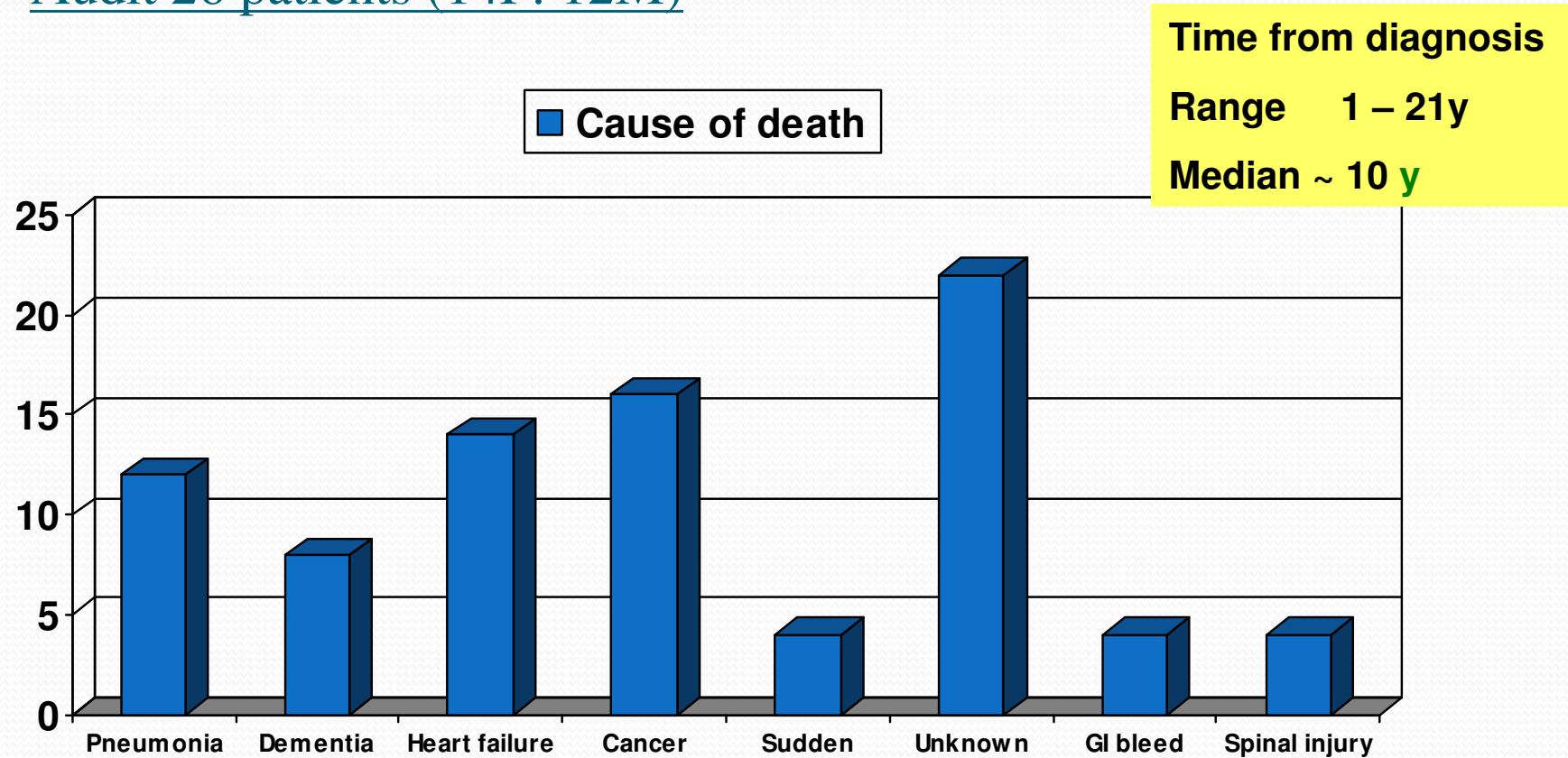
# PALLIATIVE CARE IN PARKINSON'S DISEASE

can we do better?

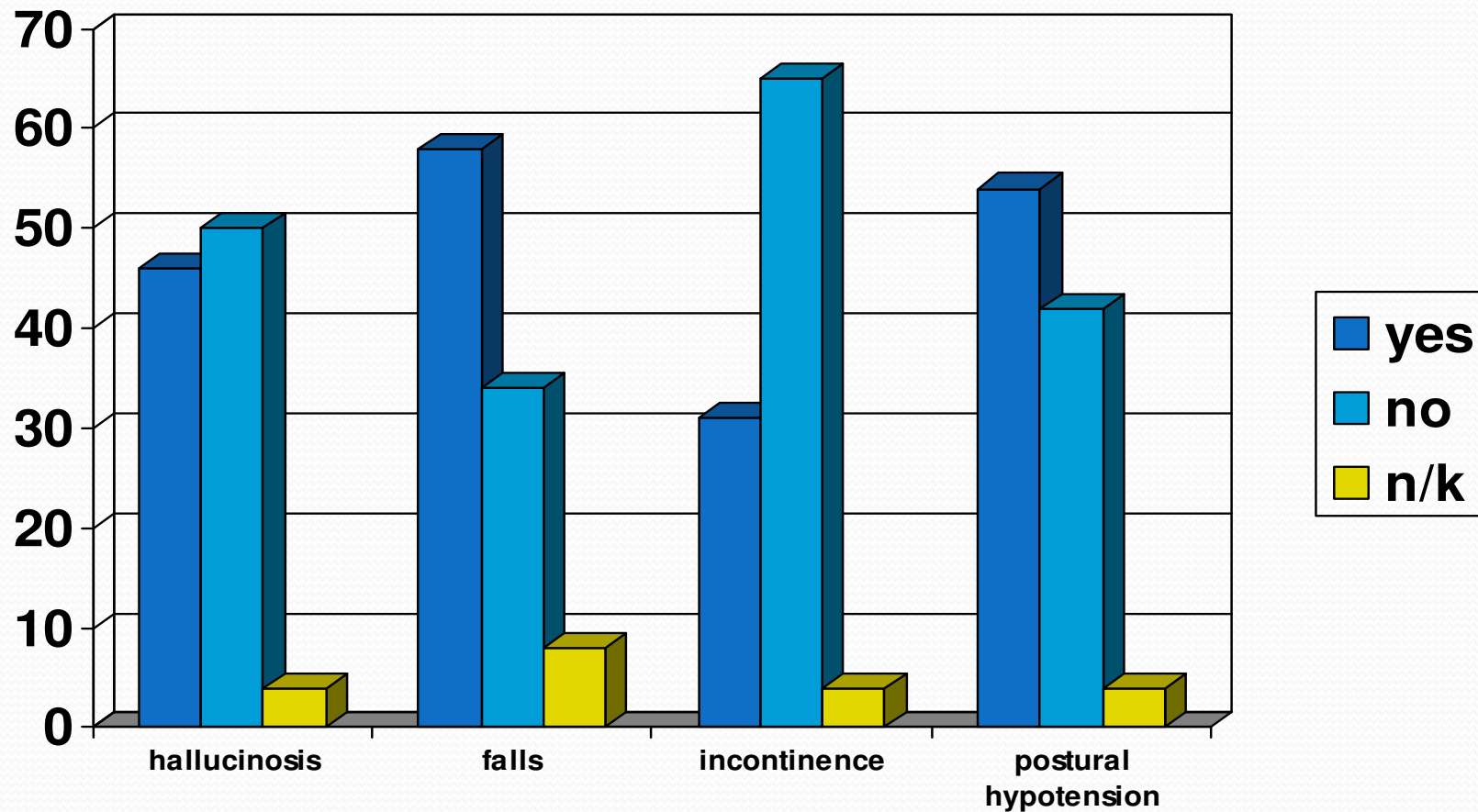
# South West Glasgow Movement Disorders Service

## Deaths

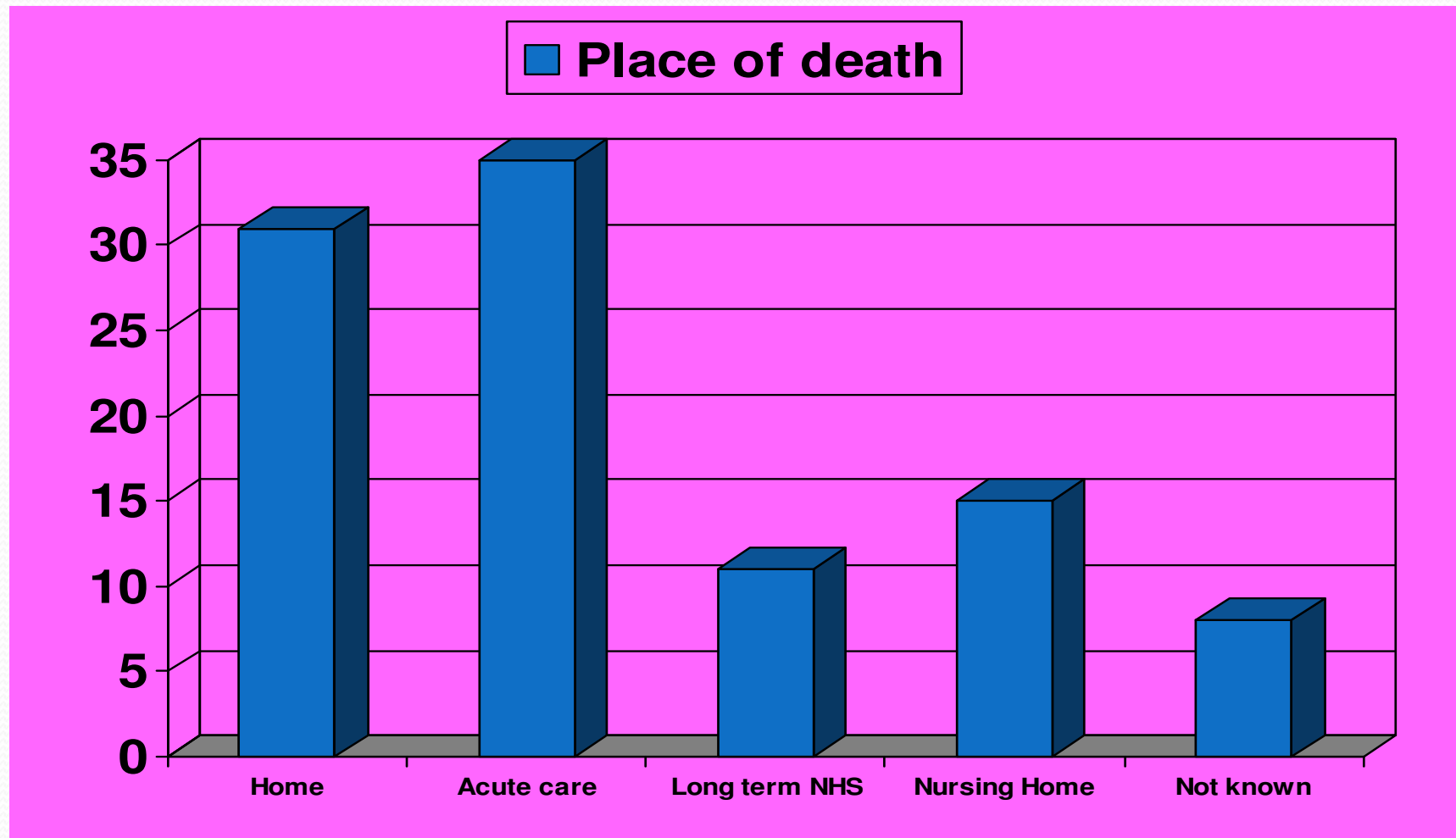
Audit 26 patients (14F: 12M)



# Presence of symptoms at last visit



# Place of death





Questions ?