Management of Parkinson's disease: challenges and impact on people's lives

Dr Nora S Vyas

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Learning Outcomes

- To increase your understanding of the signs and symptoms of Parkinson's disease.
- To understand the needs of people living with and caring for people with Parkinson's disease.
- To identify the challenges associated with the symptoms of Parkinson's, the side effects of the medication, and to dispel any myths surrounding Parkinson's.
- To learn about the resources available to improve the quality of life of people with Parkinson's and their carers.

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Parkinson's: overview

- A chronic, progressive, multi-system, neurodegenerative process which has effects on motor and autonomic function, cognitive processing and emotion
- Significant decrease in dopaminergic neurons in substantia nigra of the midbrain
- Diagnosis is clinical, no biomarkers or confirmatory tests available as yet.

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Essay on the Shaking Palsy

"....involuntary tremulous motion, with lessened muscular power, in parts not in action ..... with a propensity to bend the trunk forward, and to pass from a walking to a running pace ..... the senses and intellect being uninjured."

Dr James Parkinson, London 1817

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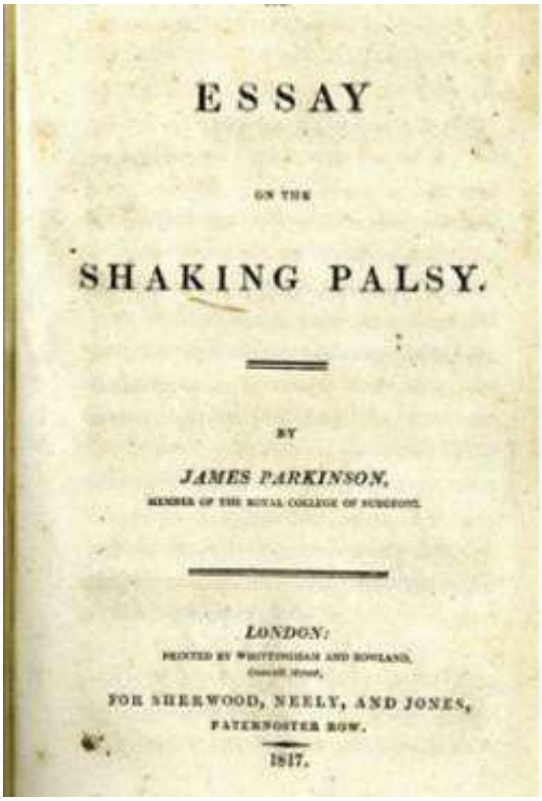

ESSAY

ON THE

SHAKING PALSY.

BY

JAMES PARKINSON,

MEMBER OF THE ROYAL COLLEGE OF SURGEONS.

LONDON:

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FOR SHERWOOD, NEELY, AND JONES,

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1817.

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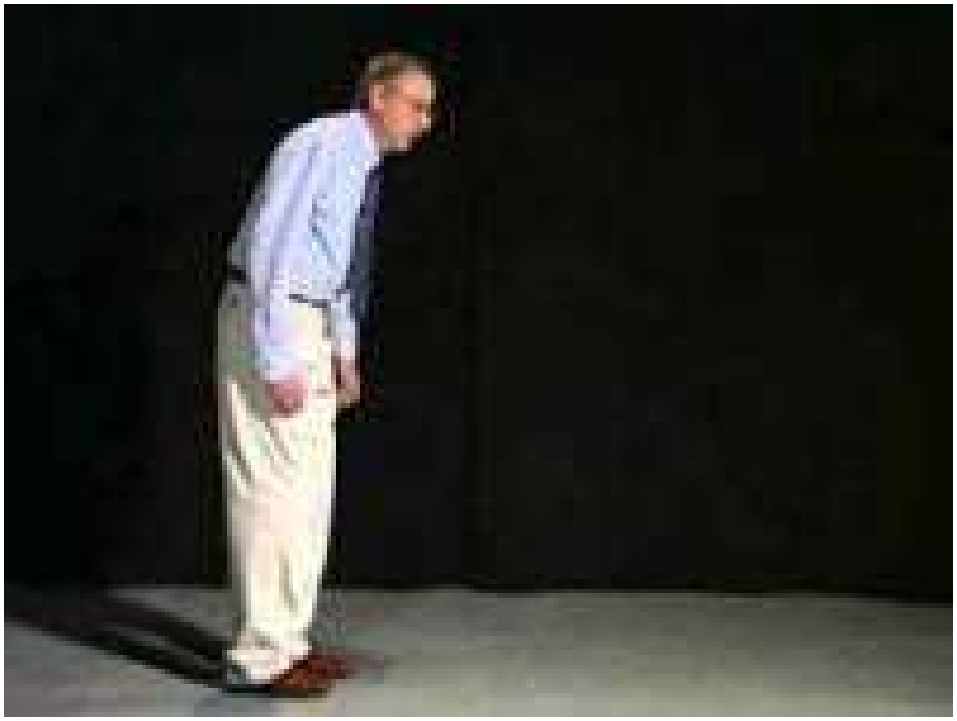

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Parkinson's: prevalence and incidence

- One in 500 of general population (One in 50 is over 80s)
- 127,000+ cases in UK* (2020: 28% increase expected)
- Most diagnosed between the ages of 55-74
- Occurs in all ethnic groups
- Statistically slightly more men than women
  - Men: 55% Women: 45%

1 in 20 diagnosed are under 40

* General Practice Research Database (GPRD) 2009

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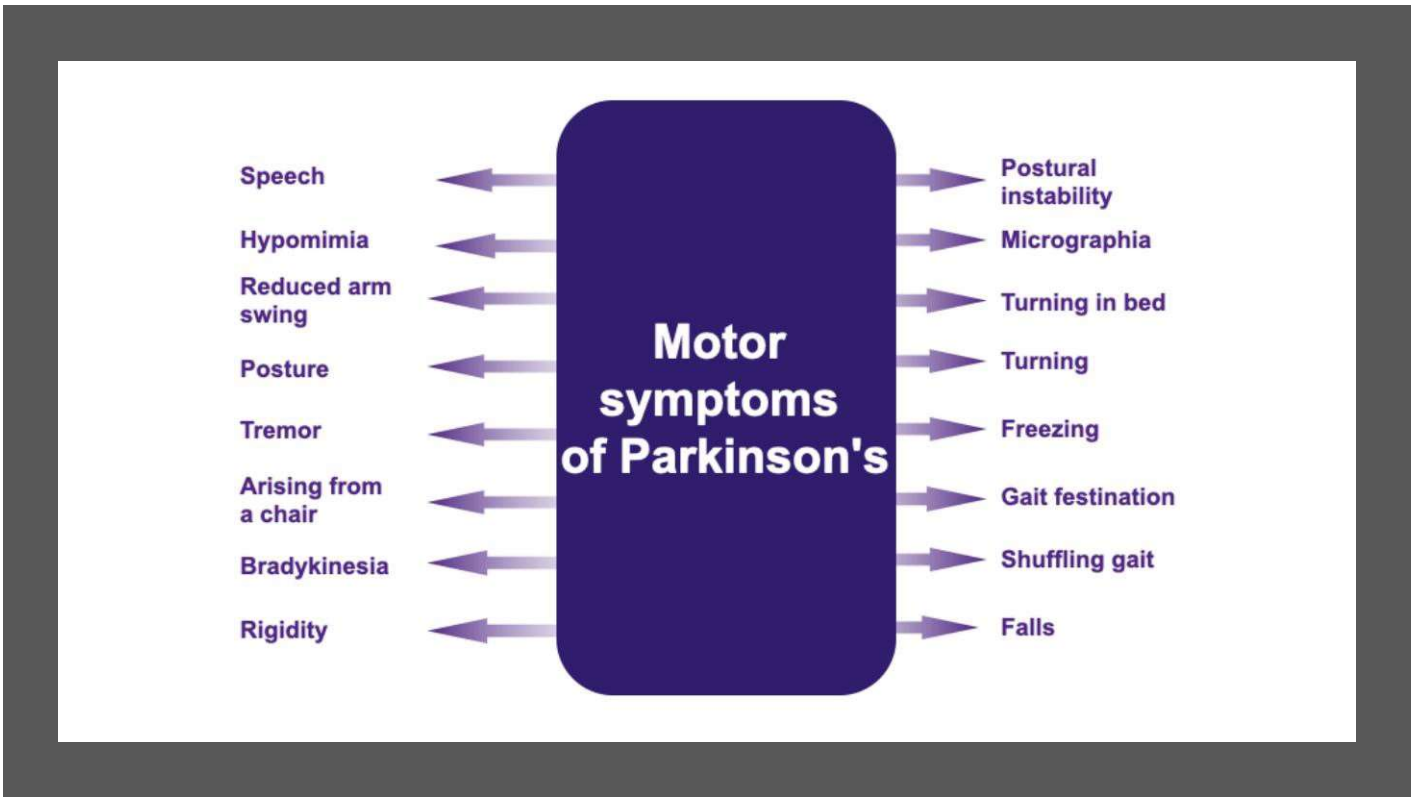

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The premotor phase of Parkinson's

- Arising in the years before the diagnosis is made
- Poor sense of smell
- Constipation
- Sleep disturbance
- Low mood

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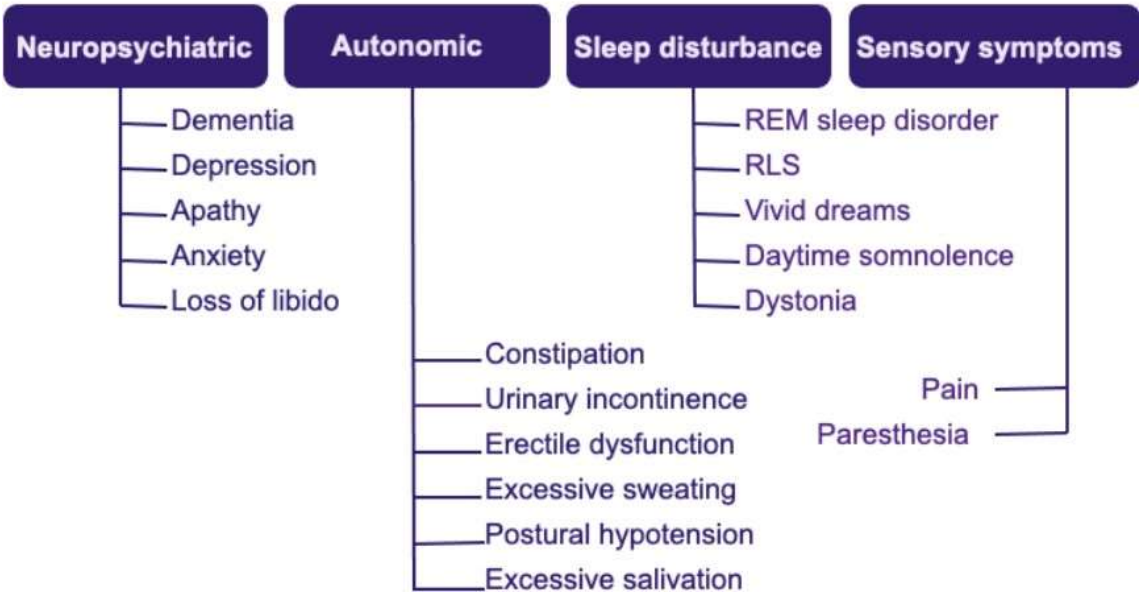
Non-motor symptoms of Parkinson's



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Non-motor symptoms questionnaire

Non-motor symptoms questionnaire

Name: ..... Date: ..... Age: .....

Centre ID: Male ☐ Female ☐

Have you experienced any of the following in the last month?

All the information you supply through this form will be treated with confidence and will only be used for the purpose for which it has been collected. Information supplied will be used for monitoring purposes. Your personal data will be processed and held in accordance with the Data Protection Act 1998. Developed and validated by the International PD Non Motor Group.

Non-movement problems in Parkinson's

The movement symptoms of Parkinson's are well known. However, other problems can sometimes occur as part of the condition or its treatment. It is important that the doctor knows about these, particularly if they are troublesome for you.

A range of problems is listed below. Please tick the box 'Yes' if you have experienced it during the past month. The doctor or nurse may ask you some questions to help decide. If you have not experienced the problem in the past month tick the 'No' box. You should answer 'No' even if you have had the problem in the past but not in the past month.

		Yes	No
1	Dribbling of saliva during the daytime.	☐	☐
2	Loss or change in your ability to taste or smell.	☐	☐
3	Difficulty swallowing food or drink or problems with choking.	☐	☐
4	Vomiting or feelings of sickness (nausea).	☐	☐
5	Constipation (less than three bowel movements a week) or having to strain to pass a stool.	☐	☐
6	Bowel (faecal) incontinence.	☐	☐
7	Feeling that your bowel emptying is incomplete after having been to the toilet.	☐	☐
8	A sense of urgency to pass urine makes you rush to the toilet.	☐	☐
9	Getting up regularly at night to pass urine.	☐	☐
10	Unexplained pains (not due to known conditions such as arthritis).	☐	☐
11	Unexplained change in weight (not due to change in diet).	☐	☐
12	Problems remembering things that have happened recently or forgetting to do things.	☐	☐
13	Loss of interest in what is happening around you or in doing things.	☐	☐

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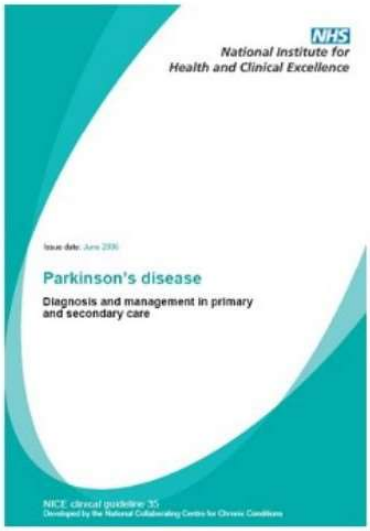
NICE Guidelines

- If PD is suspected, a patient should quickly be referred – untreated – to a neurologist or to a geriatrician with a special interest in Parkinson's
- Referral time should be no more than 6 weeks and should not exceed 2 weeks in cases where the condition is severe or complex



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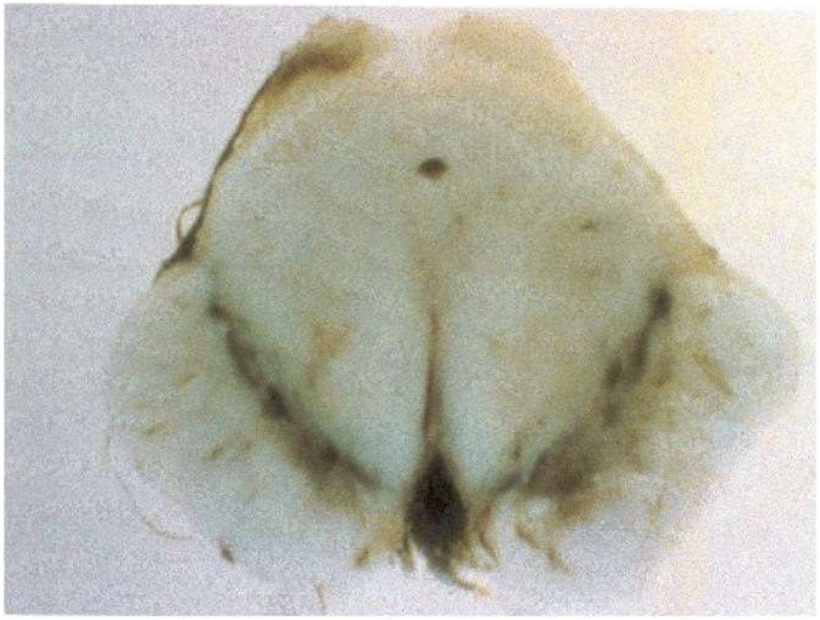

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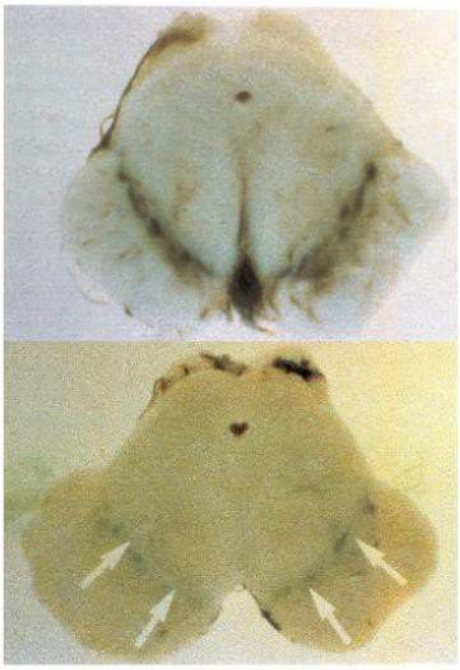
Control

Patient with PD



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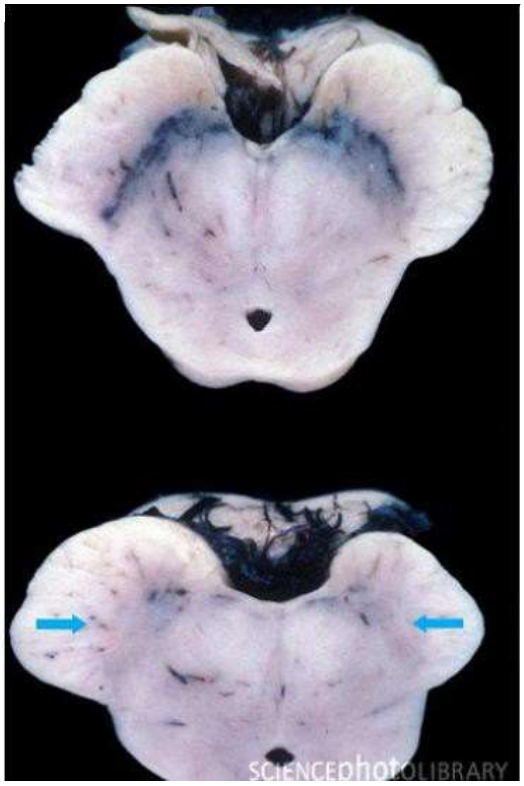
Control

Patient with Parkinson's



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Parkinsonism

- Classic - idiopathic Parkinson's (around 85% of cases)
- Atypical - Parkinson's plus syndromes
  - Multiple-System Atrophy (MSA)
  - Progressive Supranuclear Palsy (PSP)
- Other Causes –
  - Drug-induced Parkinson's – neuroleptic drugs/anti-emetics
  - Post Encephalitic Parkinson's
  - Trauma
  - Toxins
  - Vascular parkinsonism

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DRUG INDUCED PARKINSON'S

- STOP All medications that cause Parkinson's
- Metoclopramide
- Maxolon
- Prochlorperazine
- Flunarizine
- Cinnarizine
- Sodium Valproate
- NB: Domperidone is an acceptable alternative for managing nausea

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Diagnosis of Parkinson's: signs and symptoms

- Slowness of movement (bradykinesia)
- Poverty of movement (hypokinesia)
  - Difficulty *starting* a movement (initiation)
  - Reduced size of movements (amplitude)
  - Lack of co-ordination of movements (sequencing)
- Stiffness (rigidity)
- Tremor (rest)

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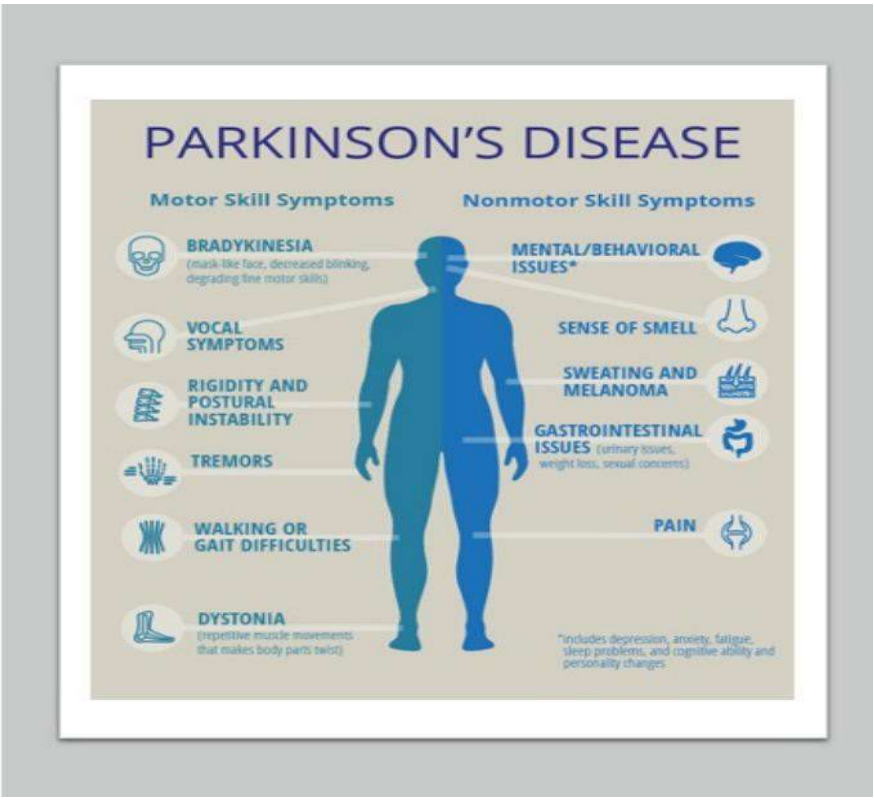
Other features

Speech problems	Constipation
Difficulties with balance	Pain
Lack of facial expression	Incontinence
Altered posture	Dementia
Swallowing problems	Depression
Handwriting problems.	Excessive tiredness
Motor freezing	Sleep disorders

- Impact of non-motor symptoms often neglected
- Importance of referral to a consultant



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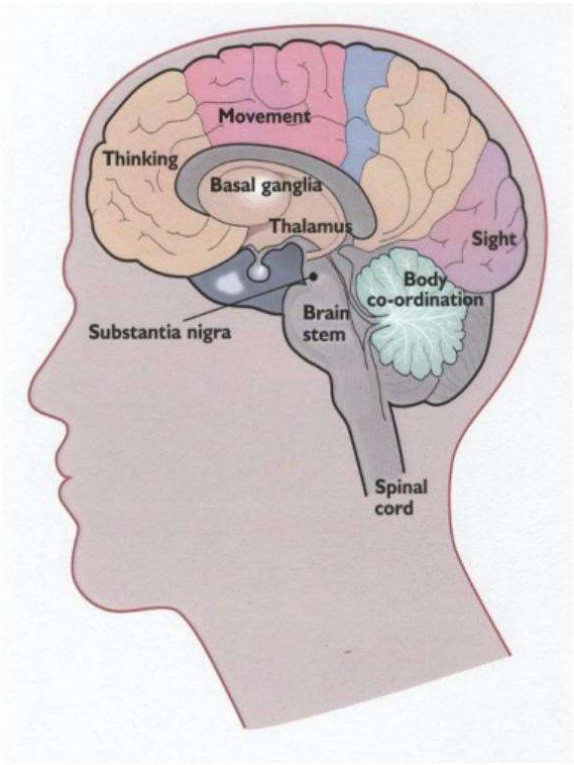

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The Impact of Parkinson's -

Slowness of Movement

- Affecting a person's
- *"Learned Voluntary Actions"*

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The impact of Parkinson's

Everyday activities that can be affected

Walking	Eating	• Cooking
Washing	Talking	• Climbing stairs
Household chores	Dressing	• Going to the toilet
Driving	Shopping	• Cleaning teeth
Dancing	Gardening	• Playing sport
Enjoying hobbies	Working	• Writing
Rising from a chair	Having Sex	• Socialising
Getting out of bed	Turning over in bed	• Answering the phone

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Swallowing
From European Survey

- 84% of people with PD had swallowing problems
- 44% had lost weight in previous 12 months
- 60% ate less than normal
- 49% felt eating was not enjoyable
- 68% were embarrassed eating
- 70% were unaware this was treatable

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The Impact of Parkinson's

- Eating & swallowing difficulties
- Drooling & Excessive sweating
- Drop in blood pressure
- Anxiety & Depression
- Dementia
- Sexual dysfunction
- Psychosis/hallucinations
- Smell/taste dysfunction
- Constipation
- Incontinence
- Handwriting
- Other fine movements
- Pain
- Turning over in bed
- Tiredness/sleep disorders
- Tremor
- Falls
- "Freezing"

Everyone is Different

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Jean and I are laughing at the same joke …

"I am trying to smile but the rigid muscles that are a symptom of my Parkinson's often make it difficult. I am not being rude.
I am not being miserable. I have Parkinson's."

Terry Kavanagh

… but I have Parkinson's.

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Communication Tips

- Please GIVE PLENTY OF TIME
- Please try not to appear rushed or angry
- Find Quiet area / avoid large groups
- Look the person in the eye, Eye contact is very important
- Suggest words…but try not to interrupt
- Don't talk about / in front of them
- Use adult language

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Management of Parkinson's disease

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Managing Parkinson's

- **Medication**
- **Surgery** (Deep brain stimulation, Lesioning & Stem cell transplants)
- **Multidisciplinary Team**
  - Physiotherapy
  - Speech & Language Therapy
  - Occupational Therapy
  - Pharmacist, Dietitian, Social worker

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Physiotherapist

- Education and support for patient and carer
- Pain management
- Early intervention
- Teach compensatory strategies and cueing techniques
- Maximise functional ability and minimise secondary complications[6]
- Assessment & treatment programmes for:
  - Gait
  - Balance
  - Posture
- Falls prevention
- Ultrasound for Apomorphine nodules

Management is through METERS

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Occupational Therapist

- Involved if there is difficulty with activities of daily living
- Maintenance of independence, safety and interaction within own environment
- Comprehensive and holistic assessment and treatment of functional activities of daily living and non-motor issues:

Practical assistance
- Self care (eating, drinking, washing and dressing)
- Domestic activities (cleaning, shopping etc)
- Functional mobility, transfers and transport
- Leisure and work
- Environment (ramps, rails)

Emotional assistance
- Cognition
- Mood
- Sleep
- Carer strain
- Advice and education

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Speech and Language Therapist

Can advise on:

- Speech
  - Exercises and techniques to help PwP control their breathing and pace their speech
  - Lee Silverman Voice Treatment[4]
  - Maintaining and improving the volume, clarity and expression of the voice
- Body and environment
  - Improving facial expression and body language
  - Posture and positioning
  - The best environment for speech and communication

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Drug treatments for Parkinson's

- Levodopa
- Dopamine agonists
- MAO-B inhibitors
- COMT inhibitors
- Glutamate antagonist
- Anticholinerginics

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- Levodopa = replaces missing Dopamine
- Sinemet (Co-Careldopa) Madopar (Co-Beneldopa) Stalevo (Combination drug)

- The most commonly prescribed
- Dopamine Agonists = Directly stimulates parts of Brain where
- Dopomine works

Bromocriptine (Parlodel) Pergolide (Celance) Cabergoline (Cabaser)
Pramipexole (Mirapexin) Ropinirole (Requip) Rotigotine (Neupro)
Apomorphine (APO-go)

- MAO-B Inhibitors = blocks enzyme which breaks down Dopamine in the Brain

Selegiline (Eldepryl, Zelapar) Rasagiline (Azilect)

COMT Inhibitors = blocks an enzyme which breaks down Levodopa

Entacapone (Comtess) Tolcapone (Tasmar)

Anticholinergics = blocks messages to the Brain

Benztropine (Cogentin) Orphenadrine (Disipal) Procyclidine (Kemadrin, Arpicolin) Trihexyphenidyl (Artane, Agitane, Broflex)

Others

Amantadine (Symmetrel)

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Common medications

- **Levodopa** is ***converted to dopamine*** and so replaces this substance which is in short supply in the body. **Sinemet (co-careldopa)and Madopar (co-beneldopa**) are the most common brands.
- Both come in a variety of strengths
- Both come in slow release formulations (which can not be crushed).
- Only Madopar comes in a dispersible formulation
- **Stalevo** is a combination of co-careldopa and Entacapone and is helpful for patients whose medication "wears off"
- Side effects -short term- nausea, postural hypotension, hallucinations
- Long term- wearing off, difficulty maintaining optimal dose, involuntary movements (dyskinesia)

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Common medications(2)

- **Dopamine agonists-** these ***mimic dopamine*** at the receptor site helping to send the signals to the muscles therefore relieving symptoms.
- Cabergoline, pergolide use with caution as increased risk fibrosis in heart valves.
- Ropinirole, Rotigotine, Pramipexole
- Sub-cutaneous medication apomorphine (complex patients)
- Transdermal patch option of **Rotigotine** may be an option when patient unable to swallow.
- **Common side-effects- day time sleepiness, nausea, postural hypotension, hallucinations, postural oedema and impulse control disorders.**

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Common medications (3)

- Other groups include MAO-B inhibitors (rasagiline, selegiline) and COMT inhibitors (entacapone, tolcapone) and amantadine. COMT inhibitors can cause gastro-intestinal disturbance.
- Rivastigmine- for Parkinson's disease dementia
- Quetiapine- used for hallucinations

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Long term

- Drug therapy does not improve the disease progression, but it does improve the patients quality of life.
- 70% of patients will get some cognitive decline. This may lead to a diagnosis of dementia.
- PD medications can cause hallucinations (but hallucinations can also be a symptom of dementia.)
- Potential deterioration in ability to perform ADLs
- May require social support or care home

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Challenges of medication

- "Honeymoon period"
- Fluctuations in response ('on-off' effect)
- Wearing off
- Nightmares/hallucinations/confusion
- Impulsive and compulsive behaviour
- Involuntary movements (dyskinesia)

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Time the medication to suit the individual

December 2011, in the JOURNAL OF ADVANCED NURSING has shown that nearly 40% of observed drug administrations involved errors.

Daiga Heisters, Head of Professional Engagement and Education at Parkinson's UK, commented: "It's vitally important that people with Parkinson's get their medication on time, every time and we know this can be a particular problem when they are admitted to hospital.

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40% of Hospital Medicines 'Involved an Error', *Able Magazine*, 02.01.12

- "*Overall, the most common error involved medicines being given at the wrong time. Whilst in many cases it is unlikely that this would cause any harm, it did include 18 of 49 doses of anti-Parkinson's medication being given over an hour late, which could have led to patients with Parkinson's not having their symptoms adequately controlled and being unable to move, get out of bed or walk down a corridor.* [...] Daiga Heisters, Head of Professional Engagement and Education at Parkinson's UK, commented: "*It's vitally important that people with Parkinson's get their medication on time, every time and we know this can be a particular problem when they are admitted to hospital.*"

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Case study - John

- John is 68 years old and has had Parkinson's for several years. He takes a number of medications, several times a day to control his symptoms.
- John wants you to know some of the challenges he faces on a typical day and wonders if there is anything you can do to help.
- The consultation starts badly; John seems to be stuck in the doorway and is unable to move for several minutes. When he eventually sits down and starts to talk to you his voice is very quiet and you do not hear all that he is saying. You begin to wonder if he understands everything you are saying to him as he often takes a long time to respond to your questions.
- John tells you that he has problems going to the toilet and that he seems to be constipated most of the time. He consequently spends a lot of time sitting on the toilet but when he gets up he often feels dizzy and has been known to fall back down again. He admits he has also fallen over on several occasions when out and about. His dizziness, sudden freezing and fear of falling have made him very nervous of going out at all. He says he especially hates being in town or where there might be crowds of people.
- He is tired for most of the day yet he has real problems sleeping at night; he frequently wakes and can't get back to sleep as he feels stuck to the bed. His wife is losing sleep as he has to nudge her to wake and help him to turn over.
- John also gets a lot of pain, particularly around his shoulders. He says it often starts around the back of his neck and seems to spread to the back of his head and his shoulders.
- He admits to you that whilst he had always been a positive person and initially resolved that he would not let Parkinson's ruin his life, he now feels he is a burden to his wife and family and wonders if there is any point in carrying on with life.

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Case study - Annie

- Annie is 58, and lives alone at home. She was diagnosed with Parkinson's nine years ago. She worked as an office cleaner until three years ago, when she had to retire due to her deteriorating health. She is on a very low income, and her home is a private rented flat with poor facilities. She has no surviving family.
- She is struggling to look after herself, has reluctantly accepted some home care, but care staff find her behaviour very challenging at times. She often has very extreme mood swings and gets very annoyed when she says staff are not helping her to take her medication on time. Staff have also often found her obsessively re-arranging her clothes in her wardrobe, and repeatedly doing this. There have been occasions recently when new staff have not been fully aware of her medication needs. Some staff have also commented to their manager that at times they think Annie could well manage to do more herself and arrive to find her very active and apparently quite self sufficient.
- Staff are particularly concerned about her hallucinations which she finds very frightening. She rarely goes out and has a poor diet of ready meals. She is often very constipated, and also complains about the problems she has turning over in bed. Most mornings she has pain in her limbs and around her shoulders.
- As far as you are aware she last saw a consultant neurologist over a year ago and has not had any support from other health professionals.

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How you can make a difference

- Encourage appropriate referrals: consultant/therapists/Parkinson's nurse/Parkinson's UK
- Understand fluctuations
- Recognise the 'on-off' phenomenon
- Respond to changing care needs
- Maintain their routine and make sure patients get their medication on time – Get It On Time
- Remember that everyone is different

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