Palliative Care in Parkinson's Disease

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Overview

- Outline a case.
- Look at available resources.
- Focus on 2016 Guidelines.
- Return to case.
- Advance care Planning.

Case

- Pat
- 82
- Hx COPD. IHD. OA.
- 13 year history of PD
- Disease progression
  - Medications titrated. Increasing intolerance.
  - Functional decline
  - Baseline
- Multiple admissions

- Admitted from acute hospital
- Treated for aspiration pneumonia
- Deterioration despite appropriate intensive medical management
- Assessed – starting to die
- Meds rationalised
- Transfer to IPU for symptomatic care
- Obtunded on admission

- Over successive days
  - More alert, following with eyes
  - No verbal response
  - Sat up. Took sips. Modified diet.
  - Very stiff.
  - Medication list from acute hospital reviewed
  - PD meds reinitiated at lower dose

- Some improvement in rigidity
- Became frightened
- Restless, unsettled
- Likely visual hallucinations
- No infection
- PD medication dose reduced with good effect. Liaison with Parkinson's CNS.
- Similar picture 2 days later – no scope for further dose reduction

Family

- Family meeting.
- Surprisingly unsurprised by fluctuating course
- Understood condition advanced and progressive.
- Troubled by hallucinations.
- Able to confirm the patients expressed wishes.
- Desire for optimising symptom control
    - Focus on comfort
    - Avoid hallucinations

Clinical Course

- CSCI low dose Midazolam
- More rigid but more settled
- Further deterioration
- No reversibility
- Started to die
- CSCI further titrated

Issues

- Patient inability to communicate in advanced disease.
- Difficult to diagnose dying phase.
- Difficulty in balancing benefit/burden of PD medications.
  - L-dopa restarted
  - Hallucinations/restlessness v rigidity
- Where to get appropriate guidance?

National Medicines Information Centre

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UPDATE ON PARKINSON'S DISEASE

- The incidence of Parkinson's disease (PD), a progressive neurodegenerative disorder, is increasing due to the ageing population
- Diagnosis is based on the presence of motor features (bradykinesia, muscle rigidity, postural instability and rest tremor) and non-motor features (e.g. constipation, mood changes, sleep and memory symptoms)
- Management consists of lifestyle modifications and multidisciplinary therapy interventions
- Each management plan should be tailored to the individual patient's PD symptoms

INTRODUCTION

Parkinson's disease (PD) is the second most common neurodegenerative disorder after Alzheimer's disease, estimated to affect > 5 million people worldwide.[1] The incidence of PD is low before the age of 50 years, with an **average age at diagnosis of 60 years**; however, it increases rapidly with age, with more recent studies suggesting a peak at around 80 years.[2,3] It occurs more rarely in younger people (known as **young-onset PD** in those aged <40 years).[2] It is slightly more common in men (lifetime estimated risk 2% vs 1.3% M:F).[3] **The condition is characterised by the presence of bradykinesia, muscle rigidity and rest tremor**; eventually impairment of postural stability occurs leading to disturbances of gait and falls.[1,4] In addition, patients with PD also have **non-motor symptoms**, including constipation, anxiety or depression, as part of the disease.[2,4,5] Due to the progressive nature of PD, costs are substantial both to the patient and his/her family or carer (in terms of reduced quality of life, and lost productivity), and to the healthcare system, because of increasing expenditure.[6]

This bulletin will outline the current national and international recommendations for the management of patients with PD and updates a previous bulletin on this topic (NMIC 2008;4:3).

Palliative care in People with **Parkinson's disease**

Guidelines for professional healthcare workers on the assessment and management of palliative care needs in Parkinson's disease and related Parkinsonian syndromes.

PALLIATIVE CARE

UCC University College Cork, Ireland Coláiste na hOllscoile Corcaigh

Centre for Gerontology and Rehabilitation
An tIonad Seaneolaíochta agus Athshlánaithe

NEUROLOGY

Parkinsons.ie Parkinson's Association of Ireland

OLDER PEOPLE

IHF Funded

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A Collective Voice for Palliative Care in Ireland since 1993

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Parkinson's Disease

- Parkinson's disease (PD) is the second most common neurodegenerative disorder after Alzheimer's disease
- Average age at diagnosis of 60 years
- Incidence increases with age, peak at age 80,
- lifetime estimated risk 2% vs 1.3% (M:F). Prevalence of Parkinson's disease is expected to more than double by 2030
- Occurs more rarely in younger people (known as young-onset PD in those aged <40 years).

Parkinson's Disease

- Although most cases of PD are sporadic, rare heritable juvenile (<20 years) and 'young-onset' PD cases, resulting from specific genetic mutations, have been identified.
- A positive family history increases the risk of developing PD compared with the general population. Role of genetic mutations in patients with familial or sporadic PD is uncertain.
- Condition is characterised by the presence of bradykinesia, muscle rigidity and rest tremor; eventually impairment of postural stability.
- Non-motor symptoms: including constipation, anxiety or depression

Motor symptoms include:

- Bradykinesia (progresses to akinesia with advanced disease)
- Rigidity (cog-wheel / lead pipe)
- Tremor at rest (pill-rolling, usually distal)
- Postural instability (progresses with advancing disease)
- Gait disturbance (e.g. leg dragging, shuffling gait, freezing of gait)
- Dysphagia, drooling (due to reduced saliva clearance), late motor complications (e.g. 'wearing-off')

Non-motor symptoms include:

- Constipation
- Neuropsychiatric (e.g. anxiety, depression, apathy, hallucinations)
- Cognitive (e.g. dementia)
- Sleep disorders (e.g. vivid dreams, broken sleep)
- Autonomic (e.g. weight loss, urinary urgency and frequency, erectile dysfunction, loss of libido, orthostatic hypotension)
- Sensory (pain)

Parkinson's Disease

- Parkinson's disease is a progressive neurodegenerative condition, resulting from the death of the dopamine producing neurons in the substantia nigra of the midbrain, and is currently incurable.
- Thus all treatment is symptomatic, with an average life expectancy post diagnosis of 15 years, although this can vary greatly.
- Parkinsonian syndromes, such as progressive supranuclear palsy (PSP) and multiple system atrophy (MSA) have shorter life expectancies, about eight years after symptom onset or within four years of diagnosis.

Relevance of Palliative Care?

- PD is a progressive life limiting illness
- Associated with significant symptom burden for patient
- Documented caregiver burden in Parkinson's disease, including depression, stress, strain, fatigue and mortality
- Palliative approach appropriate from outset
  - Improve quality of life
  - Patient and family
  - Holistic care
  - Complement but not replace other treatments

- Does a palliative care approach mean a referral to the specialist palliative care team?

Palliative Care Needs Assessment Guidance

National Clinical Programme for Palliative Care, Clinical Strategy and Programmes Division

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

PALLIATIVE CARE

2014

Role of Specialist Palliative Care

Eligibility criteria for referral to specialist palliative care services

Patients with both:

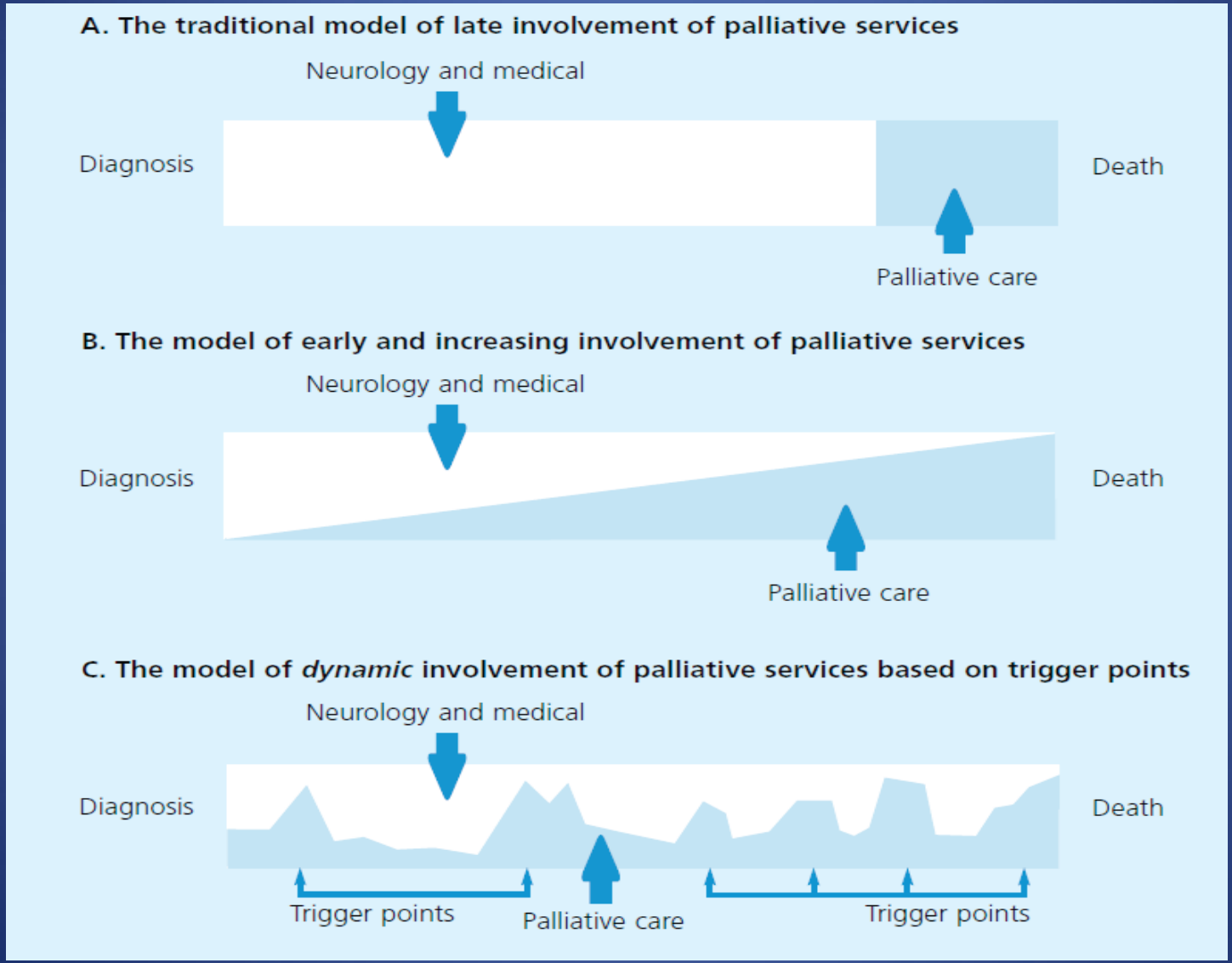
- a life-limiting condition and,
- current or anticipated complexities relating to symptom control, end of life care planning or other physical, psychosocial or spiritual care needs that cannot reasonably be met by the current care provider(s).

- Frequent assessment in advanced disease recommended.
- How do we know if a patient has advanced PD?

Advanced Disease

- Advanced phase 2.2 years on average
  - Less in PSP, MSA (more sudden and rapid decline)
- Advanced phase may be defined by:
  - Presence of advanced comorbidity.
  - Inability to tolerate adequate dopaminergic therapy.
  - Unsuitable for surgery.
- Advanced phase should trigger frequent assessments for unmet palliative care needs.
- EOLC – Where death imminent (may be hours, days, or even weeks in PD).
- Palliative care should integrate with usual care

Dynamic Involvement



Multidisciplinary Care

- Best model from Scarborough, UK and Alberta, Canada.
  - Close links between neurology/geriatrics, rehabilitation and palliative care
  - Designated point of contact
  - Needs assessment
  - Proper flow communication

Communication and Care Planning

- Advanced care planning enhances quality of care
  - Allow informed decision making
  - Realistic expectations
  - Avoid inappropriately burdensome interventions
- There may be patient/family reluctance, but often HCW reluctance
- Need to happen early in disease
- Document and communicate to MDT

Physical Care

- Motor symptoms AND non motor symptoms
- Rigidity/Stiffness
  - Disease progression, variability of response, increased intolerance, decreasing efficacy
  - Balance rigidity versus agitation/hallucinations/somnolence

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L-dopa (plus DDCI): L-dopa + carbidopa L-dopa + benserazide **L-dopa intestinal gel** (Duodopa®)	L-dopa crosses the blood-brain barrier → converted to dopamine in CNS → improves rigidity and bradykinesia (variable effect on tremor).	Mainstay of treatment for PD, most effective treatment for motor symptoms. Most PD patients have good initial response. [Dose should be titrated upwards slowly].	Diarrhoea, nausea, vomiting, anorexia. Abnormal dreams, hallucinations, depression. Hypotension, chest pain. Dyskinesias, "on-off" bradykinetic episodes. Impulsive/compulsive problems e.g. punding (pre-occupied repetitive behaviours). Risk of NMS on sudden treatment withdrawal.
Dopamine agonists ropinirole pramipexole rotigotine (patch) [bromocriptine cabergoline**] Apomorphine [solution for S/C injection / infusion]	Stimulate dopamine receptors directly (selectivity for dopamine receptors varies according to the dopamine agonist). Stimulates dopamine receptors (D1 and D2) directly.	As monotherapy in early PD to delay need for L-dopa therapy. As add-on to L-dopa therapy to boost therapeutic effect or when "on-off" fluctuations responses to L-dopa occur. [Dose should be titrated upwards slowly]. Treatment of "on-off" motor fluctuations in PD, which are not sufficiently controlled by oral medication. [Under specialist supervision].	Somnolence, insomnia, hallucinations, abnormal dreams. **Symptoms of impulse control disorders. Sudden onset of sleep during daytime.** Hypotension. Risk of NMS on sudden treatment withdrawal. [Long-term use → risk of pleuro / pericardial / retro-peritoneal / cardiac valve fibrosis with **ergot derivatives** bromocriptine and cabergoline]. **Apomorphine** requires concomitant domperidone at the start of treatment (to ↓ GI upset) → risk of **QT prolongation**. Before start of treatment need to check for patient risk factors for ↑ QT interval.
MAO-B inhibitors selegiline rasagiline safinamide***§	Irreversible MAO-B inhibitors which block degradation of dopamine in the CNS.	As monotherapy to delay need for L-dopa (early/mild stage PD). As add-on to L-dopa therapy to boost therapeutic effect or when on-off fluctuations responses to L-dopa occur. [Dose should be titrated upwards slowly].	Dyskinesias, hallucinations, depression, headache, sleep disorders. Angina pectoris / hypotension. Symptoms of impulse control disorders. Risk of DDI with other medicines – check SmPC for full details*. [↑ LFTs and risk of retinal problems with safinamide].
COMT inhibitors entacapone entacapone / L-dopa / carbidopa (combination) opicapone § [*tolcapone***]	Act peripherally to ↓ breakdown of dopamine → ↑ availability of dopamine in CNS. Requires the presence of L-dopa for effect.	Used in combination with L-dopa when end-of-dose motor fluctuations cannot be stabilised by L-dopa alone. [*Tolcapone licensed as second-line choice only because of risk of hepatotoxicity*].	Diarrhoea, nausea, abdominal pain, vomiting / constipation. Insomnia, hallucinations, confusion, somnolence. Dyskinesias. Angina pectoris. Rarely ↑ LFTs [*Tolcapone associated with ↑ hepatotoxicity*]. Risk of NMS on sudden withdrawal of treatment.
Anticholinergic agents biperiden procyclidine	Block muscarinic receptors in the CNS. [Non-dopaminergic agents].	Useful in counteracting muscular rigidity and tremor in PD. [Not first-line because of toxicity profile, especially in older patients].	Dry mouth, constipation, nausea / vomiting. Dizziness, impaired cognition, agitation, confusion, hallucinations. Urinary retention. Blurred vision, risk of ↑ intraocular pressure.

Rigidity / Stiffness

- Ensure dopaminergic medication given on time
- If dysphagia,
  - Regular levodopa/carbidopa (Sinement) crushed or dissolved. (More frequent/lower doses may be needed.)
  - Convert from extended release preparations eg Stalevo containing entacapone (COMT I).
  - Consider rotigotine (DA) transdermal patches.
- At EOL, CSCI Midazolam

Pain

- Treat rigidity as appropriate
- Not all pain PD related, identify reversible causes (e.g. urinary retention).
- Non-pharmacological
    - Positioning/postural changes
    - Nursing/OT/Physio
- Pharmacological
    - Appropriate to use WHO analgesic ladder for cancer pain as a guide
    - Monitor for constipation
    - Assess for neuropathic pain, consider anti-convulsants or anti-depressants.

Dyspnoea

- Look for reversible causes (CCF, pneumonia)
- Primarily caused by respiratory muscle weakness, and restrictive lung deficits
  - Non-Pharmacological. Breathing techniques, fan.
  - Pharmacological. Opioids. Benzodiazepines for associated anxiety.
- At end of life, treat secretions with positioning, avoid over hydration, consider trial of anti-secretory, ideally prophylactically.

Dysphagia

- Dysphagia in up to 80%
- Silent aspiration common
- Early SALT assessment and management
  - Modify consistency (food and liquid)
  - Co-ordinate meal times with “on” times

Nausea

- Consider dehydration, constipation, infection, drug causes.
  - Consider dopaminergic medications with food (but less absorbtion).
  - Avoid metoclopramide, prochloperazine (dopamine antagonism).
  - Consider domperidone (po or pr)(assess cardiac risk/benefit)
  - Ondansetron second line (constipation)
  - Cyclizine may be considered (with caution – may worsen Parkinsonism).

Fatigue & Sleep

- Fatigue can occur at any stage. Sleep disorders in up to 90%
  - Good sleep hygiene
  - Review medications
  - Accurate history of pattern/causes
    - If due to rigidity, consider medication increase
    - If due to dopaminergic meds, trial earlier dose

Dementia

- PD associated with increased risk cognitive decline and dementia
- Cholinesterase inhibitors can be helpful.
- A reason to consider advance care planning early in the disease trajectory.

Hallucinations

- Visual hallucinations common in PD – may be well tolerated in some.
- If sudden worsening, accompanied by fluctuating cognition, attention, consciousness – consider delirium.
- If distressing – gradually withdraw antiparkinsonian medication in order of
    - Anticholinergics, amantadine, MAOB inhibs, COMPT inhibs, dopamine agonists, and finally minimise levodopa.
    - Balance of physical disability v mental clarity.
- Avoid typical antipsychotics (Haloperidol).
- Consider atypical antipsychotic (particularly quetiapine).

Depression

- 60% of patients with PD (direct disease component but also loss of function, role, QOL.)
- Significant impact on QOL.
- Can be difficult to diagnose (fatigue, anergia, sleep disturbance).
- Complementary therapy, good sleep, better exercise important. CBT for moderate depression.
- SSRI's most appropriate pharmacotherapy for moderate/severe depression.
- Mirtazepine may aid sleep, but can worsen nightmares.

Social care

- Multiple losses
  - Loss of independence/abilities
- Multiple fears
  - Fear of disorder
  - Fear of the future
  - Fears for the family
  - Fear of palliative care
- Advice and support
  - Counselling
  - Financial advice
  - OT/Physio – independence/mobility

Spiritual Care

- Personal search for meaning and purpose.
- Not synonymous with religion.
- Key aspect – listen to individual narrative
- Many HCW feel ill equipped.
- Referral to SPC/Chaplaincy may be appropriate for unmet spiritual needs.

Advance Care Planning & Communication

- Many potentially life-prolonging treatments are used in advanced PD without knowledge of the person's wishes.
  - These include treatment of serious infections with antibiotics, and intravenous / subcutaneous hydration.
  - Less commonly enteral nutrition, artificial ventilation and CPR.
- People's preferences should always be considered.
- These may differ from the preferences of the family /carer.

Advance Care Planning & Communication

- Start difficult discussions at or soon after diagnosis by exploring peoples' attitudes and views before decisions have to be made and any possible cognitive change has developed.
- Recognise that this is a process rather than a single event and will need to be revisited in future consultations.
- Difficult discussions are often at the heart of compassionate care,
  - respecting the person's autonomy and helping them to make choices in keeping with their own circumstances, attitudes and beliefs

Advance Care Planning & Communication

- “Has it been helpful in the past to know a bit more about your condition?”
- “Do you like to know what is happening with your condition?”
- “Would it be helpful to talk about how this condition may progress from here?”
- “How have you been coping with things since you found it harder to swallow?”
- “What you would like to see happen from here?”

Our Patient

- Significant comorbiditiesWe see this intolerance of dopamine replacement.
- Patient and family distressed by hallucinations.
- Helpful that patient/family had discussed his preferences..
- The dying phase of PD can be unpredictable
  - Can be days or weeks rather than hours or days

Typical presenting symptoms of sudden deterioration in PD

Presenting symptoms of sudden deterioration	Top 10 causes of sudden deterioration in PD
Motor: ↑tremor/rigidity; ↑ walking problems; freezing of gait; poor balance/falls; dyskinesia. **Non-motor:** confusion / delirium; hallucinations; daytime sleepiness.	Constipation; intercurrent illness / infection / surgery; dehydration; medication non-compliance; use of dopamine antagonists; stress-related episode; depression; acute / chronic pain; anxiety / panic attack; sleep disturbances.

Summary

- Important to optimise function and quality of life in people with PD.
- There are benefits of a palliative care approach for people with PD.
- Resources are available for HCW on adopting a palliative care approach in PD.
- People with PD should have access to SPC services, when required.
- Cognitive impairment / dementia common in late PD.
- Timely care planning and intervention necessary.
- Often need to balance physical disability v mental clarity when adjusting medications.

Palliative Care in Parkinson's Disease

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