Pathways

A
PARADIGM
FOR DISEASE
MANAGEMENT
IN
Parkinson's
Disease

Clinical diagnosis

Parkinson's disease (PD) is a progressive, neuro degenerative condition which results from death of the dopamine- containing cells in the substantia nigra. The condition affects approximately 120,000 people in the UK, with an annual incidence of 10,000 newly diagnosed cases.

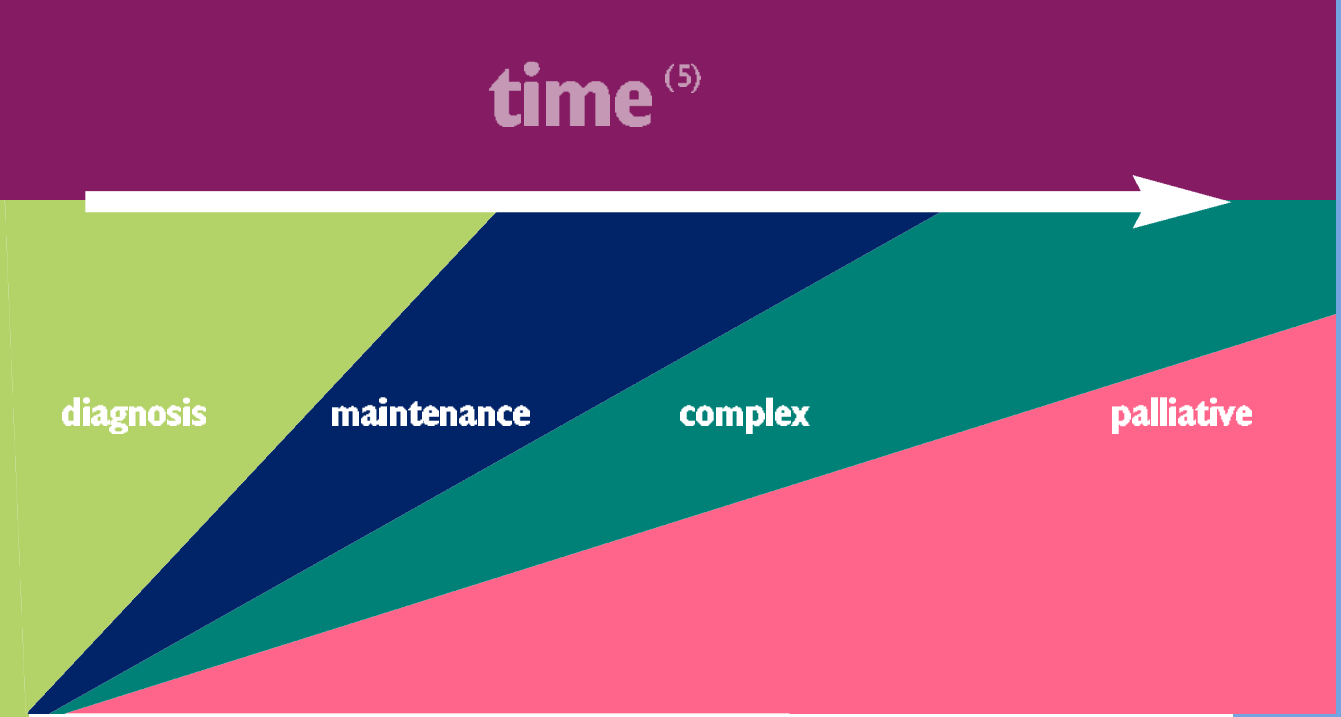
Symptoms of the disease include slowness of movement, rigidity and rest tremor. Although the disease is predominantly a movement disorder impairing mobility, other problems frequently develop which include psychiatric disturbances like depression and dementia.

In order to understand the disease more easily in 1998 a disease management model Pathways was developed as a lingua franca for education. This defined the disease into 4 stages:

- **Diagnosis**
- **Maintenance**
- **Complex**
- **Palliative**

Times spent in these stages varies (1) and care needs throughout will need to be based on the individuals increasing dependency but as the disease progresses patients will require increasing support from both health and social services. 38% of direct care costs are apportioned to the NHS and 34% to social services (2) with care costs per patient ranging from £4,000- £19,000 per annum depending on the care setting.

Over time it has increasingly been recognised that individuals have palliative care needs throughout the course of the disease. Rather than the disease being compartmentalised into rigid stages a palliative care approach is required throughout the disease and elements of care and support introduced based on individual assessment. See time course *



Time course

Course

The scale of the problem

Parkinson's disease affect different aspects of life at differing times of the disease process, which in turn determines the appropriate care required to improve patients and carers' quality of life, while maximizing NHS cost effectiveness.

A Health economy of 500,000 patients will have:

A Health Economy of around 500,000 patient will have around 1,500 people with PD in any one year around 55 new people will be diagnosed of which 8-10 will be under 60 years of age and a few will be under 40 years

The greatest single costs relating to managing these individuals are in younger patients and long term institutional care in older patients.

- Mean direct costs per patient @ age:
  - c£4,000 per annum below 65 years
  - c£9,400 per annum over 85 years
- Mean direct annual costs a disease severity
  - Hoehn & Yahr stage (0-1) c£3000
  - stage 5 c£18,400
  - greater than five fold increase
- Within direct costs, the NHS accounts on average for 38% and Social Services for 35%
- The rise in Social Services costs is particularly influenced by H&Y stage, reaching c£7,000 pa at stage V
- Within NHS costs, the split between primary care (incl drugs) and secondary care is roughly equal across age groups.
- However, across H&Y stages secondary care accounts for an increasing proportion (27% in stages 0-1, 62% in stage V)
- Drug expenditure accounts for 11% of overall costs in younger and 6% costs in older patients.
- The multiple regression equation explains 49% of total direct costs. Accommodation status has most influence on these costs, a move to long term care implying an annual increase of c£11,600.

Hoehn & Yahr staging scale used (3)

Stages

- From first recognition of symptoms/sign/problem
- Diagnosis not established or accepted

- Established diagnosis of PD
- Reconciled to diagnosis
- No drugs or single drug 4 or less doses/day
- Or 2 drugs but stable medication for >3/12
- Absence of postural instability

- Drugs more than 5 doses or more than 2 drugs
- Inability to accept diagnosis despite adequate information and education
- Any parenteral medications (apomorphine)
- Dyskinesia
- Neuro-surgery considered
- Psychiatric manifestations >mild symptoms of depression/anxiety/hallucinations/psychosis
- Autonomic problems – hypotension either drug or non-drug induced
- Unstable co-morbidities
- Frequent changes to medication (<3/12)
- Significant dysphagia or aspiration

* Consider Multiple System Atrophy from diagnosis

- Inability to tolerate adequate dopaminergic therapy
- Unsuitable for surgery
- Advanced co-morbidity (life threatening or disabling)

It should be noted that patients may move between stages either way. This will be affected by drug therapy and the patient's general condition

Diagnosis

Average time in stage 1.6 ± 1.5 (PD) 1.8 ± 1.8 (atypical)

REFERRAL TO EXPERT FOR ACCURATE DIAGNOSIS

People with suspected PD should be referred quickly and untreated to a specialist with expertise in the differential diagnosis of this condition. Suspected mild PD should be seen within 6 weeks; new referrals in later disease or with more complex problems require an appointment within 2 weeks.

AIMS

- Development of disease awareness
- Reduction in symptoms and distress
- Acceptance of diagnosis

ASSESSMENT (Medical and nursing)

- To ascertain accurate diagnosis
- Evaluate disability
- Assess support available
- Estimate patient understanding

MANAGEMENT

- Develop Care plan
- Consider multidisciplinary referral
- Physiotherapist
  - Occupational therapist
  - Speech & language therapist
  - Dietician
- Ensure regular access to rehabilitation interventions
- Provide patient carer information on employment, driving, finances

STAGE OUTCOMES

- Reduction in patient distress
- Effective symptom control

NICE RECOMMENDS

Refer untreated to a specialist who makes and reviews diagnosis:

- Using UK PD brain bank criteria
- Consider 123I-FP-CIT SPECT
- Specialist should review diagnosis at regular intervals (6-12 months)

It is not possible to identify a universal first choice drug therapy for people with early PD. The choice of drug first prescribed should take into account:

- Clinical and lifestyle characteristics
- Patient preferences

Referral to a Parkinson's disease nurse specialist for:

- Monitoring and altering medication appropriately
- Provide a continuing point of contact for patient support, including home visits
- Acting as a reliable source of information about clinical and social matters of concern to people with PD and their carers.

Maintenance

Average time in stage 5.9 ± 4.8 (PD) 3.0 ± 2.0 (atypical)

AIMS

- Morbidity relief
- Maintenance of function and self care
- Promotion of normal activities
- Re assessment
- Avoid unnecessary medical dependency
- Reduce symptoms
- Avoid side effects
- Alert for complications;
  - Constipation
  - Postural hypotension

MANAGEMENT

- Review care plan
- Provide patient/carer education (Consider Expert patient/carer programmes)
- Assistance and advice with medication single or dual
- Drug therapy
- Ensure regular access to rehabilitation interventions regular review meetings with therapists;
  - Physiotherapy
  - Occupational therapy
  - Speech and language therapists.

OUTCOMES

- Symptom reduction
- Treatment concordance
- Maintenance and promotion of normal activities

NICE RECOMMENDS

Consider management of non-motor symptoms in particular:

- Dementia
- Psychosis
- Depression
- Sleep Disorder

Provide regular access to specialist care particularly for:

- Clinical monitoring and medication adjustment
- A continuing point of contact for support, including home visits when needed these may be provided by a PD nurse specialist

Consider access to rehabilitation therapies, particularly to:

- Maintain independence, including activities of daily living and ensure home safety
- Help balance, flexibility, gait, movement initiation
- Enhance aerobic activity
- Assess and manage communication and swallowing

Complex

Average time in stage 4.9 ± 4.4 (PD) 3.5 ± 3.5 (atypical)

AIMS

- Morbidity relief
- Maintenance of function and self-care despite advancing disease
- Assistance and adaptation of environment to promote daily living activities
- Re-assessment because of increasing disability and complexity
- Symptom control

MANAGEMENT

- Increasing complex drug management from disease management & medication side effects
- Advice on practical problems, management of non- motor symptoms & prevention of complications
- Referral liaison may be required as in stage I +
  - Psychiatrist/CPN
  - Neuro surgery

OUTCOMES

- Optimum symptom control
- Minimalisation of disability
- Treatment concordance

NICE RECOMMENDS

It is not possible to identify a universal first choice adjuvant drug therapy for people with later PD. The choice of drug prescribed should take into account:

- Clinical and lifestyle characteristics
- Patient preference

Consider apomorphine in those with severe motor complications unresponsive to oral medication:

- Intermittent injections to reduce refractory on-offs
- Continuous subcutaneous infusion to reduce off time and dyskinesia

Consider surgery:

- Bilateral STN stimulation for suitable people refractory to best medical therapy
- Thalamic stimulation for people with severe tremor who are not suitable for STN stimulation

NON MOTOR SYMPTOMS

- Balance
- Sleep disturbance
- Anxiety/worry
- Urinary problems
- Memory failure and confusional episodes
- Bowel problems
- Dribbling saliva
- Speech difficulties

Palliative

Average time in stage 2.2 ± 2.2 (PD) 1.5 ± 1.2 (atypical)

AIMS

- Relief of symptoms and distress in patients and carers
- Reassessment
- Morbidity relief
- Maintenance of dignity and remaining function despite advancing disease
- Avoidance of treatment related problems
- Symptom control

MANAGEMENT

- Consider referral to specialist palliative care team
- Advice on administration of medication
- Progressive dopaminergic drug withdrawal
- Analgesia
- Sedation
- Counselling/ psychology/psychiatry
- Prevention of complications
- Urinary incontinence
- Constipation
- Motor fluctuations

OUTCOMES

- Absence of distress
- Maintenance of dignity
- Symptoms controlled

NICE RECOMMENDS

Management of non motor symptoms

- Dementia
- Psycosis
- Depression
- Sleep disorder

Provide regular access to specialist care particularly for:

- Clinical monitoring and medication adjustment
- A continuing point of contact for support, including home visits when needed these may be provided by a PD nurse specialist

Consider access to rehabilitation therapies, particularly to:

- Maintain independence, including activities of daily living and ensure home safety
- Help balance, flexibility, gait, movement initiation
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- Assess and manage communication and swallowing

REFERENCES AND RESOURCES

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