Ontario Long-Term Care Clinician Conference 2023

Advanced Parkinson Disease, Dementia and Neuropalliative Care

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University of Alberta

DISCLOSURES - JL

Membership on advisory boards or speakers' bureaus	Caregiver-Centered Care Physician Education Advisory	Guide the co-design process for a Caregiver-centered care education mnodule and resource for family medicine (small honorarium)
Funded grants, research, or clinical trials	North Alberta Clinical Family Medicine Fund The NRV strategic clinical network research grant - MS, PD and Quality of Care in Alberta	$7500 2 year grant to develop course for Fam Med in Parkinson's care $20000 frant to develop evidence based electronic order set, rules and education

Objectives

- Review the picture of Advanced parkinsonism (Atypical syndromes and Advanced Parkinson disease)
- Review approach to discuss goals of care in advanced parkinsonism
- Learn how to “balance symptom management” (physical vs. mental) in advanced parkinsonism
- Recognize the evidence for Neuropalliative Care
- Learn the basics of providing Neuropalliative Care in your practice

Commercial Support Disclosure

- This program has received no financial or in-kind support from any commercial or other organization

Parkinson Disease: M-A-N

Motor Symptoms:

Early

Slow Movement

Tremor Stiff Muscles Shuffling Gait

Moderate

→ Slower movement

Axial symptoms

Advanced

Freezing of Gait, Falls

Postural Instability

Swallowing Difficulty

Autonomic Dysfunction:

Bowel: Constipation (60%) (pre-motor) - slow GI motility, GERD

Bladder: (30%) Nocturia, OAB

BP: (30%) Orthostatic Hypotension

Neuropsychiatric Symptoms:

Sleep disorders (60%): RLS, RBD(50%), OSA

Depression and/or Anxiety (40%)

Dementia, psychosis

RBD (often preceding PD by median of 14 years)

Hoehn and Yahr stages in PD

- Stage 1: unilateral
- Stage 2: bilateral
- stage 3: Bilateral with impaired of balance
- Stage 4: need gait aids, gait Impairment (FOG) and postural instability predominate.
- less responsive to PD treatment (likely related to nondopaminergic cell loss)
  → Increased caregiver stress
- Stage 5: bed bound or wheelchair dependent

Comprehensive Parkinson's Assessment: M-A-N

Motor:

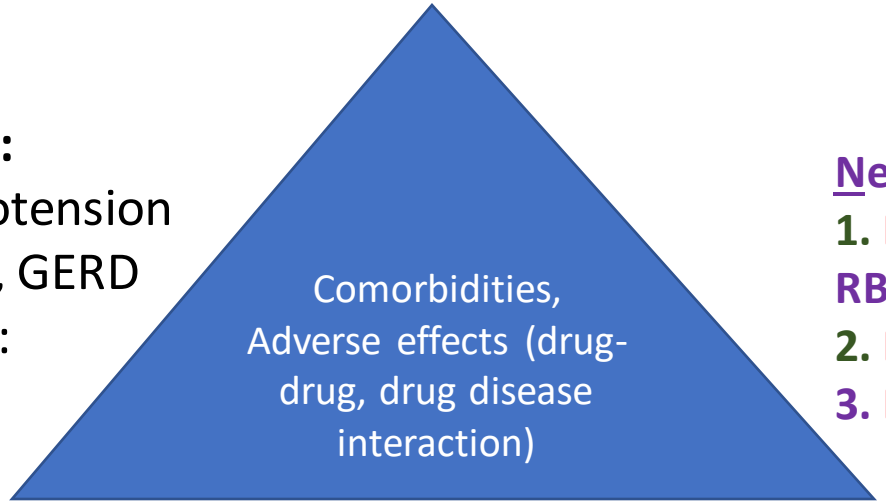
1. TRAP, Motor fluctuations

2. Bone health, falls risk

3. Swallowing problem

Autonomic:

1. **B**P: Orthostatic Hypotension
2. **B**owel: Constipation, GERD
3. **B**ladder Dysfunction: OAB, UTI



Neuropsychiatric:

1. Disturbed Sleep: RBD,RLS,OSA

2. Depression/Anxiety

3. Dementia/ Psychosis

Atypical Neurological Features

Presence of these features in early stages of disease can help distinguish PD from other parkinsonian syndromes: (CGPD 2012 – AAN Level B):

- Falls at presentation and early in course
- Poor response to levodopa
- Symmetry at onset
- Lack of tremor
- Dysautonomia (urinary ugency/incontinence and fecal incontinence, urinary retention requiring catherization, erectile dysfunction and orthostatic hypotension)
- Rapid progression (to Hoehn and Yahr Stage 3 at 3 y)

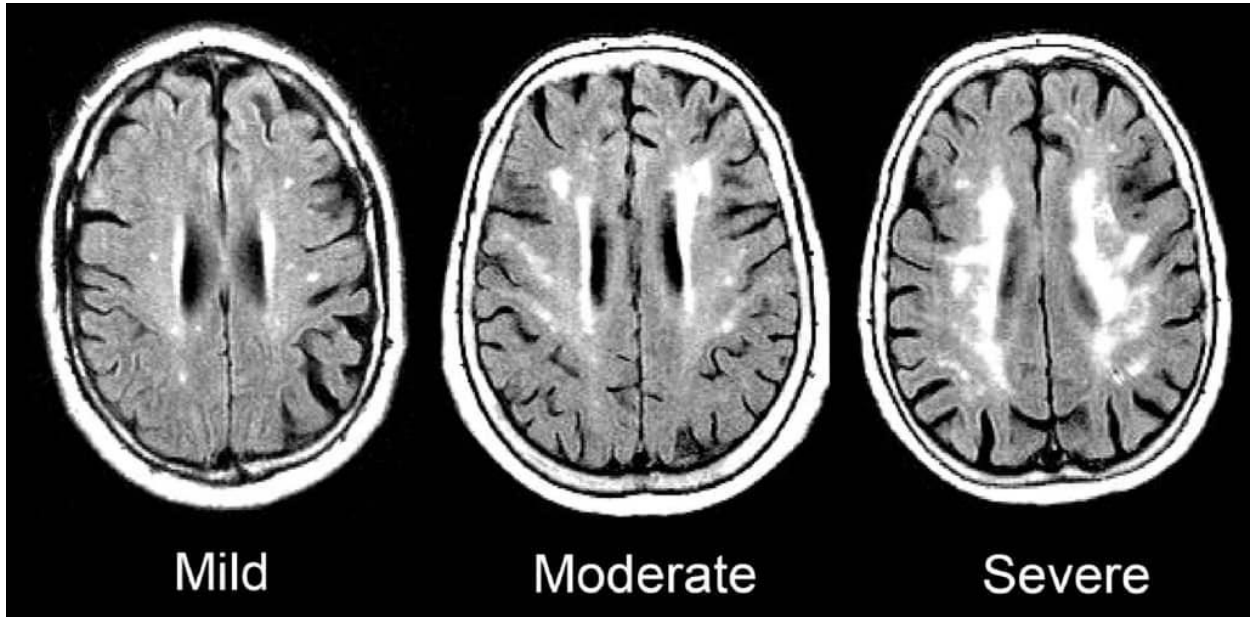
CGPD – Canadian Guidelines on Parkinson Disease
Download at parkinsonclinicalguidelines.ca

Atypical Parkinsonism

- Progressive supranuclear palsy (PSP)
- Multiple Systems Atrophy (MSA-P, MSA-C)
- Dementia with Lewy Bodies (DLB)
- Corticobasal syndrome/degeneration (CBS/CBD)

Vascular parkinsonism + dementia

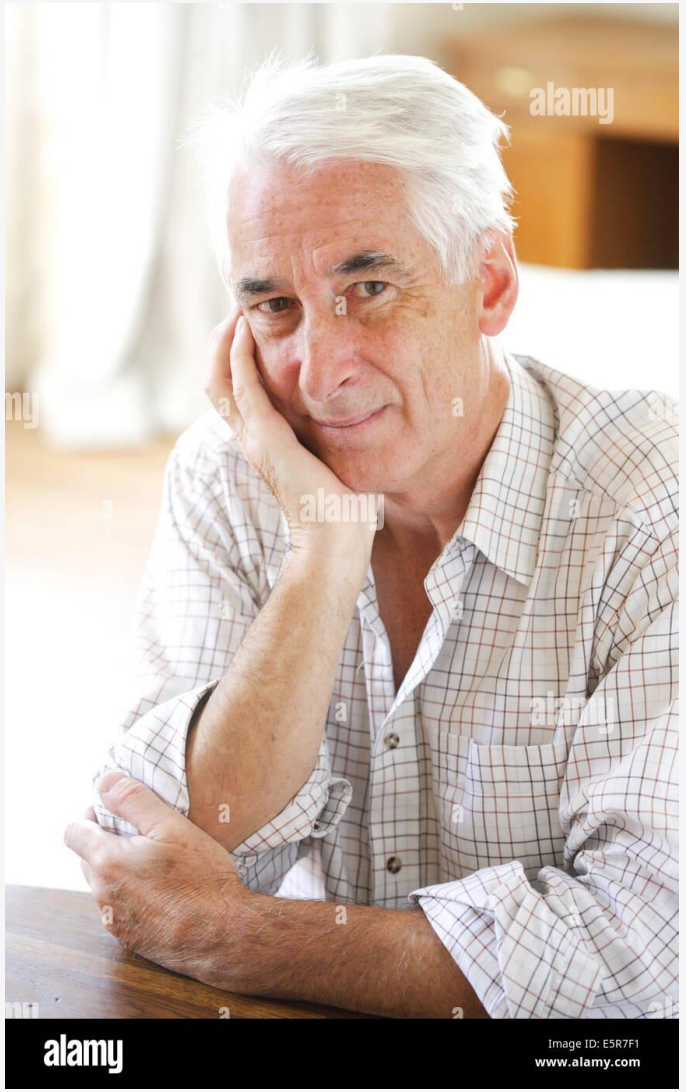
- More common than recognized
- Soft signs of parkinsonism – most LE and gait apraxia, with preserved UE function
- Dementia – mostly executive dysfunction
- No "LB" symptoms, eg. REM sleep disorder, visual hallucinations, dysautonomia
- Vascular risk factor and evidence of cortical /subcortical vascular disease on brain imaging
- Progressive frailty and CVD can result in poor UE function/praxis as well



Case: Paul

65 yo retired accountant admitted to LTC with 20 years of PD, on long term regimen:

- **Rasagiline 1mg daily (MAO-B Inh)**
- **Pramipexole 1.5mg tid (Dopamine Agonist)**
- **Levodopa/carbidopa 100/25 2 tab po 5 times daily**
- **Entacapone 200 mg po 5 times daily**
- **Levocarb CR 100/25 po hs**
- **Amantadine 100mg bid for dyskinesia**
- **Quetiapine 25 mg po hs**
- Followed by MDP in Toronto, Hoehn and Yahr Stage 4, Clinical frailty scale 7, needs assistance for all ADLs, could not ambulate without walker and 1 person assist
- Wife lives at home and visits often. They have 2 children.



Hoehn and Yahr stages

- Stage 1: unilateral
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- less responsive to PD treatment (likely related to nondopaminergic cell loss)
  → Increased caregiver stress
- Stage 5: bed bound or wheelchair dependent

Atypical Parkinsonism progress within 3 years to stage 3

Case Study: Paul

- 3-4 years of hallucinations, initially benign, with recent worsening, paranoia and frequent falls when he tries to get up to fight “people” and “freezes”
- Progressive confusion and fluctuates in attention
- He won’t go to sleep at night and is agitated, calling nurses frequently.
- Hypersexual with nurses – inappropriate touching and comments.
- He has lost 15 lb recently and has moderate almost continuous writhing dyskinesias

Weight loss / low body weight

Dopaminergic drug dosing is weight based

WEIGHT LOSS = excessive dopamine stimulation with same dose →

increases psychosis, dyskinesias & **Impulse Control Disorder**

Dyskinesias drive more weight loss → vicious cycle

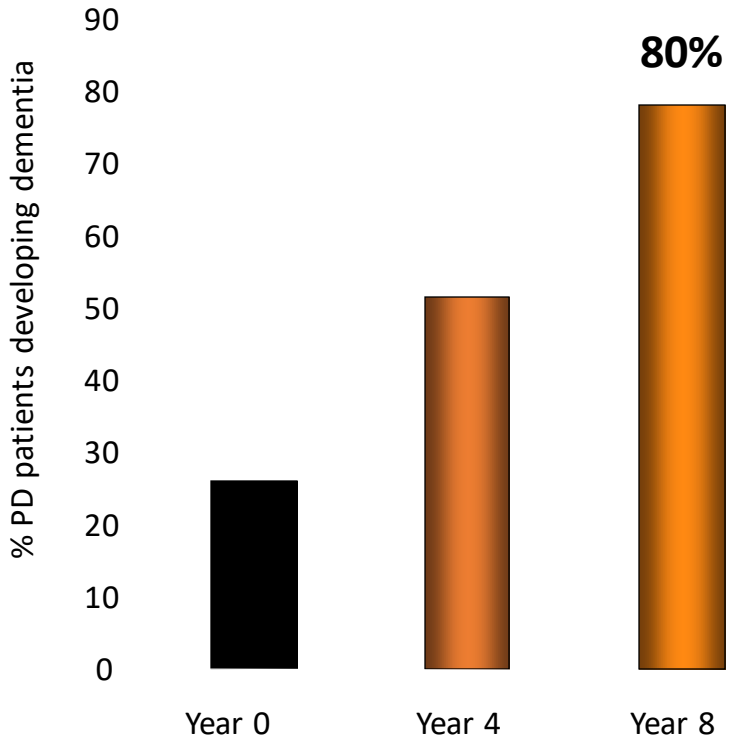
Parkinson's Disease Dementia (PDD)

Always assess for PDD in PD psychosis – often underdiagnosed

Increased risk with age & PD duration

Donepezil and Rivastigmine are indicated for PD dementia

Alternative: Memantine



Aarsland D et al. Arch Neurol 2003;60:387–92

Cummings JL. J Geriatr Psych Neurol 1988;1:24-36

CGPD 2019 – Cognition and psychosis

- Presence of psychosis (hallucinations (usually visual)/ delusions) should trigger a *medical and cognitive assessment* (GPP; NICE)
- *Reduce/stop culprit medications:*
  - *stop anticholinergics -> taper off amantadine -> reduce/stop dopamine agonists - > reduce/stop MAO-B/entacapone -> lastly reduce levodopa (CGPD 2019 - EFNS GPP*)*
- If PDD diagnosed, then consider donepezil or rivastigmine(A, EFNS), galantamine (C; EFNS); memantine can be added or sub'd if CI not tolerated or efficacious(C, EFNS)
- Avoid all antipsychotics other than quetiapine (GPP) and clozapine (A; CFNS); Clozapine needs monitoring.

Freezing of Gait (gait apraxia)

- Extremely difficult problem with multiple contributing factors, including deficits in attention, cognition, anxiety, motor programming
- Common in *dementia, late-stage PD, as well as atypical parkinsonism, vascular parkinsonism/dementia, NPH*
- Disruption of frontal subcortical circuits
- Physical therapy, gait training, improvement of balance can help
- Multiple therapies are being investigated: some evidence for use of CI: Donepezil, Rivastigmine (improvement of attention)

Goal resetting

- Patients and families are used to focusing on MOTOR symptoms as main goal of treatment
- Increasing cognitive impairment and neuropsychiatric complications in late-stage PD = TIME TO RESET GOALS
- Excessive dopaminergic stimulation to “keep patient on” is only making psychosis and impulsivity worse → ie. Overall function worse
- *Prioritize “mental clarity” and QOL (meaningful interactions with family) over “being ON all the time”*
- Adjunctive relaxation techniques to manage anxiety with wearing off
- Reassess GCD in graduated process

Case: Paul

Management:

- *Gradually* taper off Pramipexole – dose decrease every 3 weeks

Pramipexole 1.5 mg tid →

1.25 mg po tid for 3 weeks →

1 mg po tid for 3 weeks →

0.75 mg tid for 3 weeks etc. till ICD/psychosis etc. abate

- Reduce amantadine to 50 mg bid by 3 weeks if dyskinesias OK
- *May* need to increase levodopa slightly to compensate for motor Sx

New medication regimen:

- Rasagiline 1 mg daily, Pramipexole 0.25 mg po tid, Levocarb 100/25 2 tab 5 times daily, Entacapone 5 times daily, Amantadine liq 50 mg bid, quetiapine 12.5 mg hs

Case Study: Paul

Psychosis & hypersexual behaviour are much improved since tapering down Pramipexole, reducing amantadine

Motor Sx “OK” – peak dose dykinesias much better, no more falls, no pain

Gained back 15 lb

MoCA 15/30;

Dx: PD dementia with fluctuations in attention and mild hallucinations

Paul's PD medications

- Rasagiline 1 mg daily
- Pramipexole 0.25 mg po tid
- Levocarb 100/25 2 tab 5 times daily 0700, 1030, 1400, 1730, 2100
- Entacapone 200 mg 5 times daily
- Levocarb CR 100/25 po hs
- Amantadine 50 mg bid
- Quetiapine 12.5 mg hs
- PEG 3350 8.5 gm daily
- Senokot 2 tab po hs

Cholinesterase Inhibitors in PD Dementia

- PDD and DLB ("Lewy Body dementias") have more cholinergic deficit than Alzheimer's disease*
- *CGPD 2019: "If PDD diagnosed, then consider donepezil or rivastigmine(A, EFNS), galantamine (C; EFNS); memantine can be added or sub'd if CI not tolerated or efficacious(C, EFNS)"*
- CI side effects:
  - orthostatic hypotension*, bradycardia, increased tremor/parkinsonism, 10% GI (nausea/vomiting/diarrhea), weight loss
- CI contraindications:
  - LBBB (definite), HB beyond first degree, >bifascicular block, severe orthostasis, weight loss/low body weight
- *Donepezil 5 mg daily cc breakfast – follow BP, ECG and weight*
- Memantine is reasonable alternative (clinical experience: about 50% improve in terms of hallucinations) - but not covered

Bohnen N et al. Cortical Cholinergic Function is more severely affected in Parkinsonian Dementia than in Alzheimer disease. Arch Neurol 2003; 60: 1745-48

Paul:
Goal of care (GoC)discussion

- Paul's POA for personal care (ON) or Personal Directive agent is his wife Wendy
- Paul's current Goal of Care is still R2 (Limited Resuscitation without chest compressions)
- At the annual review, you talk to Wendy, enact the Personal Directive (or document his incapacity) as Paul is no longer capable of making the GoC decision
- Wendy – "Do people die of Parkinson's disease? He was told he will die of something else and PD won't kill him"

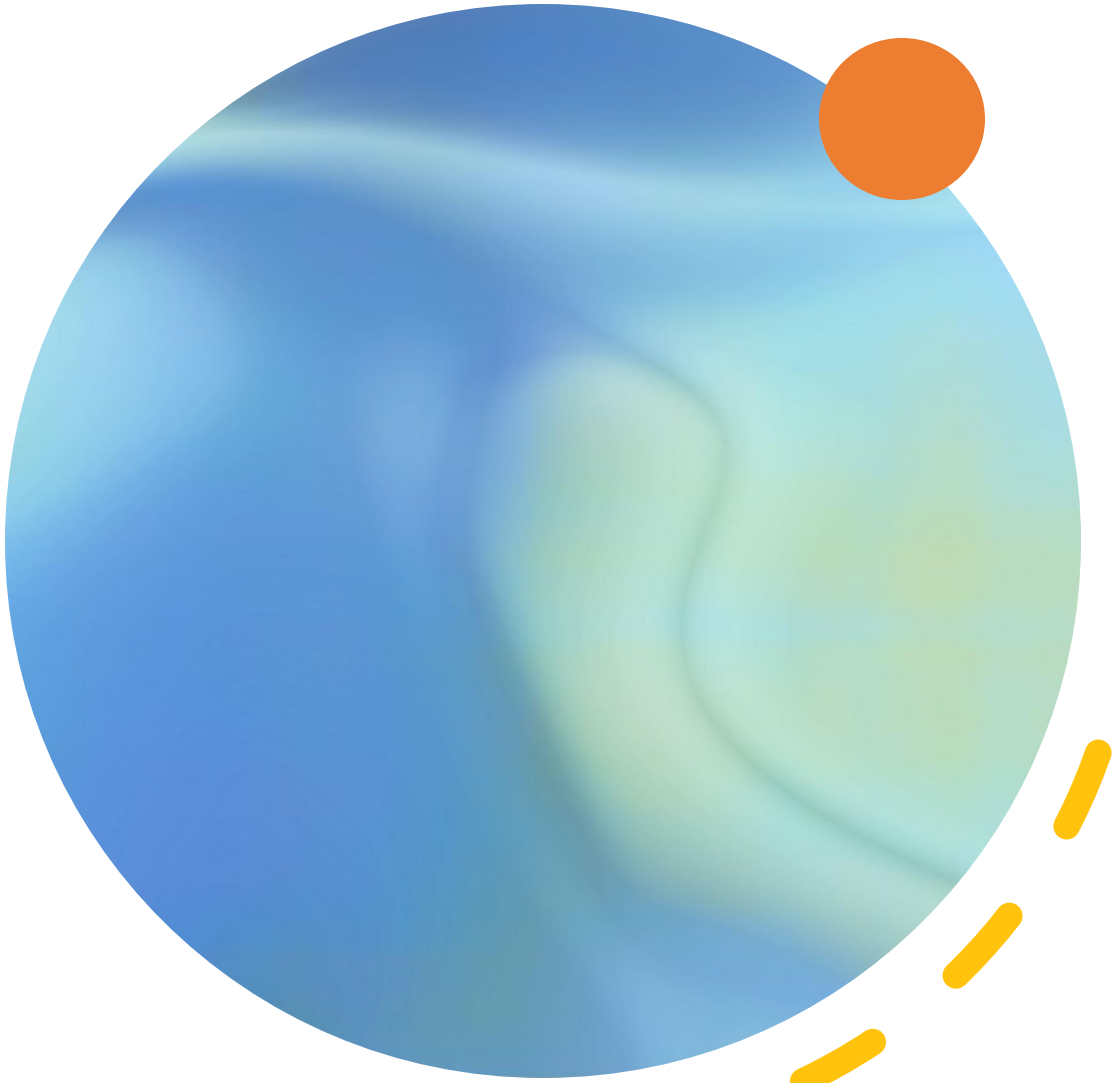
Case Study: Paul

Taper off Pramipexole 0.125 mg po tid for 2 weeks then stop

Taper down Amantadine **by 50mg per week – watch for emergent dyskinesias**

Reduce Rasagiline to 0.5 mg daily

Add Donepezil after baseline ECG – watch for low BP and weight loss



Neuropalliative Care

CGPD 2019 - Palliative care

- People with PD and their family should be offered opportunities to **discuss prognosis, promoting their priorities, shared decision-making and patient-centred care.** (D, NICE)
- Patients and caregivers should be given info (verbal and written) about progression, possible drug A/E, ACP, **what could happen at end of life, support services** (D; NICE)
- **Consider referring people at any stage of PD to palliative care team to allow the opportunity to discuss end of life choices and care**. (D; NICE)
- **Palliative care requirements of people with PD, including options in MAID should be considered throughout all phases of disease** (CGPD 2019 – GPP; CAN)

Main messages:

- Start conversation early with patient and family
- May need repeated conversations to shift treatment goals and GoC/resus status
- Allow time to accept losses
- Involve palliative care team, spiritual support if available

When does the “Palliative stage” start in PD?

NPF panel:

- Hoehn and Yahr Stage 3 + (consensus amongst PD specialists)
- Presence of dementia, psychosis, or significant caregiver strain (1)

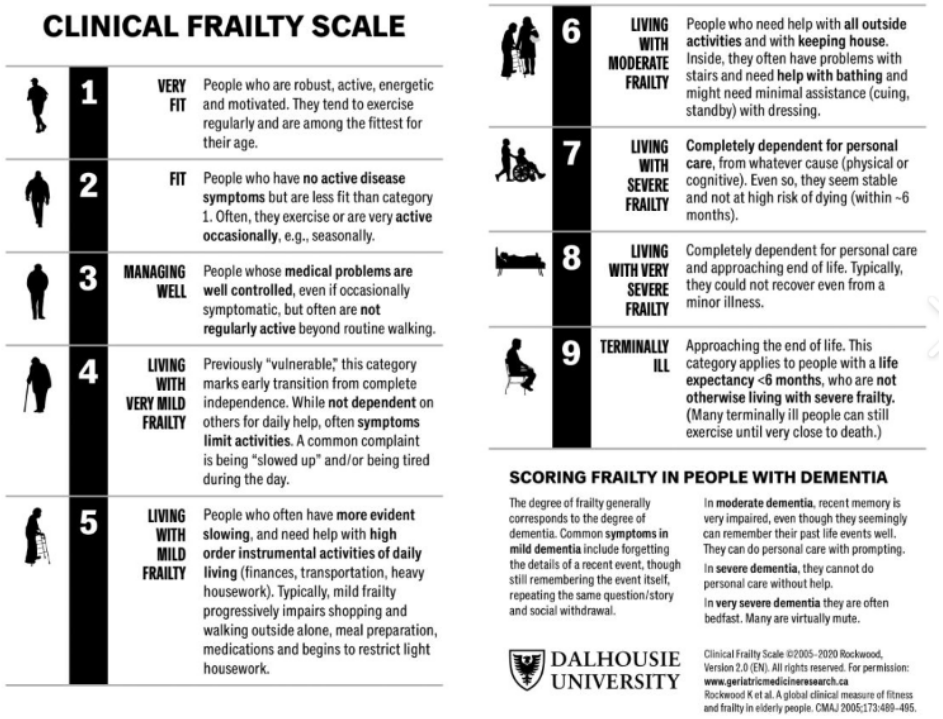
By 10 years of disease, features increasing caregiver burden – ie. Falls (55%), cognitive decline (80%) are common (2)

25% in LTC by 15 years – due to mostly non-motor (ie. Non-dopa responsive features)(3)

Advanced parkinsonism (PD, MSA, PSP) at H + Y stage 3 -5 – 50% DIE in 1 year (4) and had practical problems “not addressed by health care team” (5)

1. Miyasaki J. Curr Neurol Neurosci Rep (2013) 13:367
2. Hassan A et al. Parkinsonism Relat Discord 2012; 18: S 10 -4
3. Hely et al. Mov Disord 2005; 20: 190-9 ; 4. Higgison et al. PLoS One. 2012: 7:e46327
5. Saleem TZ et al. Palliat Med 2012; doi: 10. 117/0269216312465783

Clinical Frailty is a strong predictor of poor health outcomes and mortality



CLINICAL FRAILTY SCALE

1	VERY FIT	People who are robust, active, energetic and motivated. They tend to exercise regularly and are among the fittest for their age.
2	FIT	People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g., seasonally.
3	MANAGING WELL	People whose **medical problems are well controlled**, even if occasionally symptomatic, but often are **not regularly active** beyond routine walking.
4	LIVING WITH VERY MILD FRAILTY	Previously "vulnerable," this category marks early transition from complete independence. While **not dependent** on others for daily help, often **symptoms limit activities**. A common complaint is being "slowed up" and/or being tired during the day.
5	LIVING WITH MILD FRAILTY	People who often have **more evident slowing**, and need help with **high order instrumental activities of daily living** (finances, transportation, heavy housework). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation, medications and begins to restrict light housework.
6	LIVING WITH MODERATE FRAILTY	People who need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.
7	LIVING WITH SEVERE FRAILTY	**Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~6 months).
8	LIVING WITH VERY SEVERE FRAILTY	Completely dependent for personal care and approaching end of life. Typically, they could not recover even from a minor illness.
9	TERMINALLY ILL	Approaching the end of life. This category applies to people with a **life expectancy <6 months**, who are **not otherwise living with severe frailty.** (Many terminally ill people can still exercise until very close to death.)

SCORING FRAILTY IN PEOPLE WITH DEMENTIA

The degree of frailty generally corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

In **very severe dementia** they are often bedfast. Many are virtually mute.

DALHOUSIE UNIVERSITY

Rockwood K et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489–495.

- **In-hospital death for CFS 5 vs. 7 is 3.4% vs. 27.4 % (9 x)**

Basic D, Stanley C. Journal of Aging and Health 27(4) 2015 : 670-685.

Long-Term Care

- High occurrence of severe Clinical Frailty (ie. 7 or higher)
- High polypharmacy
- High comorbid burden
- Patients with PD/parkinsonism who are admitted to LTC are in Hoehn and Yahr stage 4 - 5 usually

You have a unique opportunity to provide Palliative Care to this population

Focus on:

- Clinical Frailty Scale
- PD stage and prognosis
- ***Poor clinical outcomes with aggressive interventions incl resuscitation***
- "What would Paul want in this case if the Paul 20 years ago could tell you?"
- Acknowledge motor Sx cannot be improved but overall QOL could with palliative approach
- Most common cause of death is **ASPIRATION PNEUMONIA**
  and **FEEDING TUBES DO NOT PREVENT IT**
- **Aspiration pneumonia – 50% of dying in 6 months from same**

Other comorbidities such as stroke and dementia

Follow up duration	Mortality rate (percent)	
	Patients with PD (%)	Patients without PD (%)
1 month	23.9	30.9
3 months	41.8	48.0
6 months	54.1	57.0
12 months	65.2	67.4
24 months	76.3	76.8
36 months	84.4	81.8
48 months	88.3	86.1
60 months	91.8	88.9

Table 4. Mortality after occurrence of aspiration pneumonia among PD patients and control group. *PD* Parkinson's disease.

Won, J.H., Byun, S.J., Oh, BM. *et al.* Risk and mortality of aspiration pneumonia in Parkinson's disease: a nationwide database study. *Sci Rep* **11**, 6597 (2021). https://doi.org/10.1038/s41598-021-86011-w

Dysphagia Interventions

- Modified diet and texture
- Swallowing strategies (chin down, 2 -3 swallows) (1)
- **Expiratory muscle strength training** and video assisted swallowing therapies may help (2)
- ***Levocarb CR, Entacapone formulas (incl Stalevo) cannot be Crushed***

1. Logemann, J. A. et al. A randomized study of three interventions for aspiration of thin liquids in patients with dementia or Parkinson's disease. (2008)
2. van Hooren, M. R., Baijens, L. W., Voskuilen, S., Oosterloo, M. & Kremer, B. Treatment efects for dysphagia in Parkinson's disease: A systematic review. Parkinsonism Relat. Disord. 20, 800–807. https://doi.org/10.1016/j.parkreldis.2014.03.026 (2014).

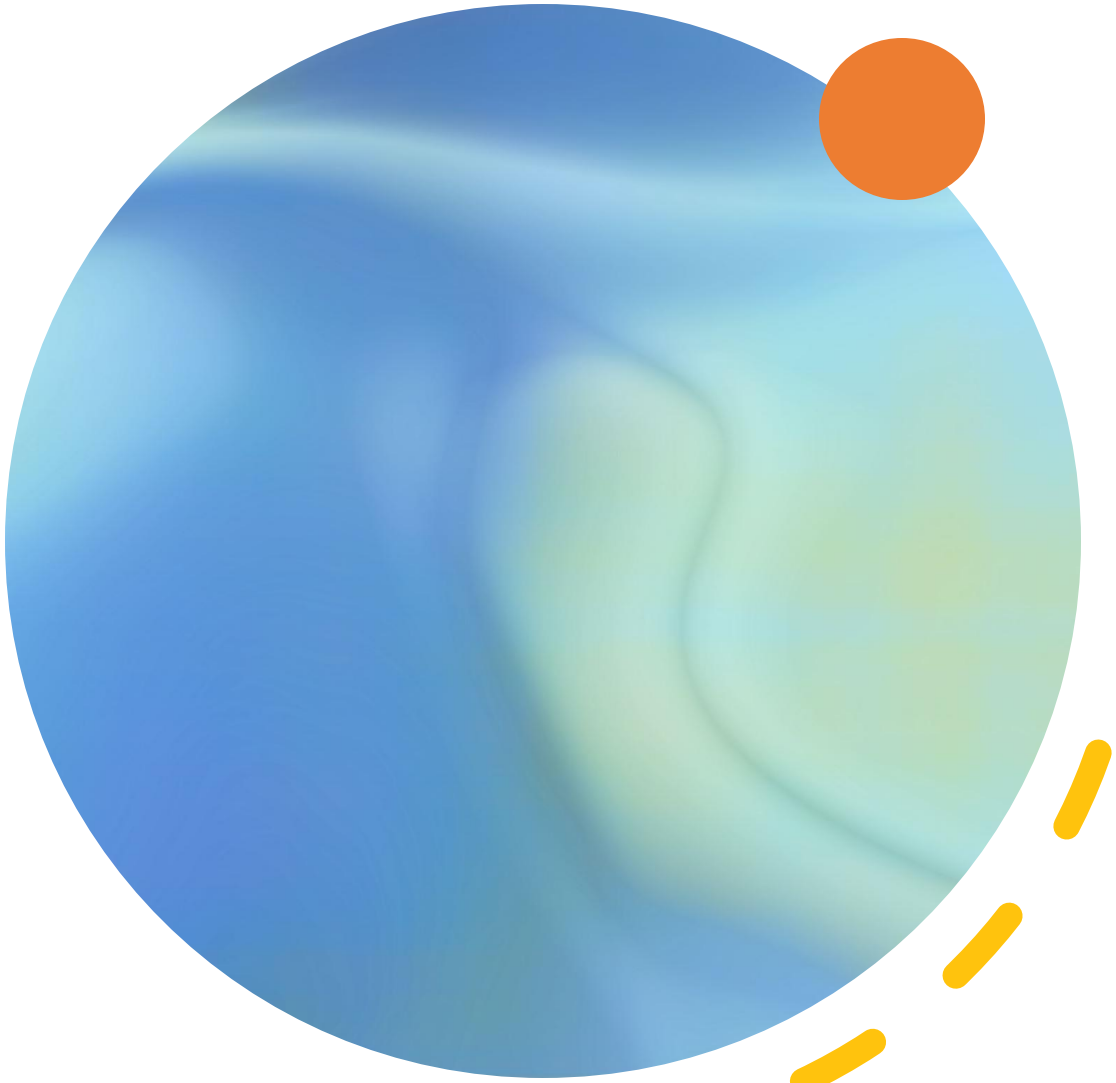
Case Study: Paul

Taper off Pramipexole 0.125 mg po tid for 2 weeks then stop

Taper down Amantadine **by 50mg per week – watch for emergent dyskinesias**

Reduce Rasagiline to 0.5 mg daily

Add Donepezil after baseline ECG – watch for low BP and weight loss



Case: Paul

- Levocarb 100/25 2 tab 5 times daily 0700, 1030, 1400, 1730, 2100
- **Entacapone 200 mg 5 times daily**
- **Levocarb CR 100/25 po hs**
- Rasagiline 0.5 mg daily
- Quetiapine 12.5 mg hs
- **PEG 3350 8.5 gm daily – cannot be thickened**
- **Senokot 2 tab po hs – cannot crush**

- Total Daily Dopa dose =

1000 mg (from levodopa IR) +

20% (200mg) (from Entacapone)

70 mg (from Levocarb CR)

=1270 mg per day

--> **250mg levocarb IR 5 times per day**

- **PEG – switch to lactulose for thickening**
- **Senna liquid in applesauce or bisacodyl supp q2d**

Most bothersome symptoms in Advanced Parkinsonism for palliation

Contents lists available at SciVerse ScienceDirect

Parkinsonism and Related Disorders

journal homepage: www.elsevier.com/locate/parkreldis

Palliative care for advanced Parkinson disease: An interdisciplinary clinic and new scale, the ESAS-PD

Janis M. Miyasaki*, J. Long, D. Mancini, E. Moro, S.H. Fox, A.E. Lang, C. Marras, R. Chen, A. Strafella, R. Arshinoff, R. Ghoche, J. Hui

The Palliative Program for Parkinson Disease and Related Disorders, The Morton and Gloria Shulman Movement Disorders Centre, Toronto Western Hospital, University of Toronto, Canada

- Constipation
- Pain
- Anxiety/depression
- “Stiffness”

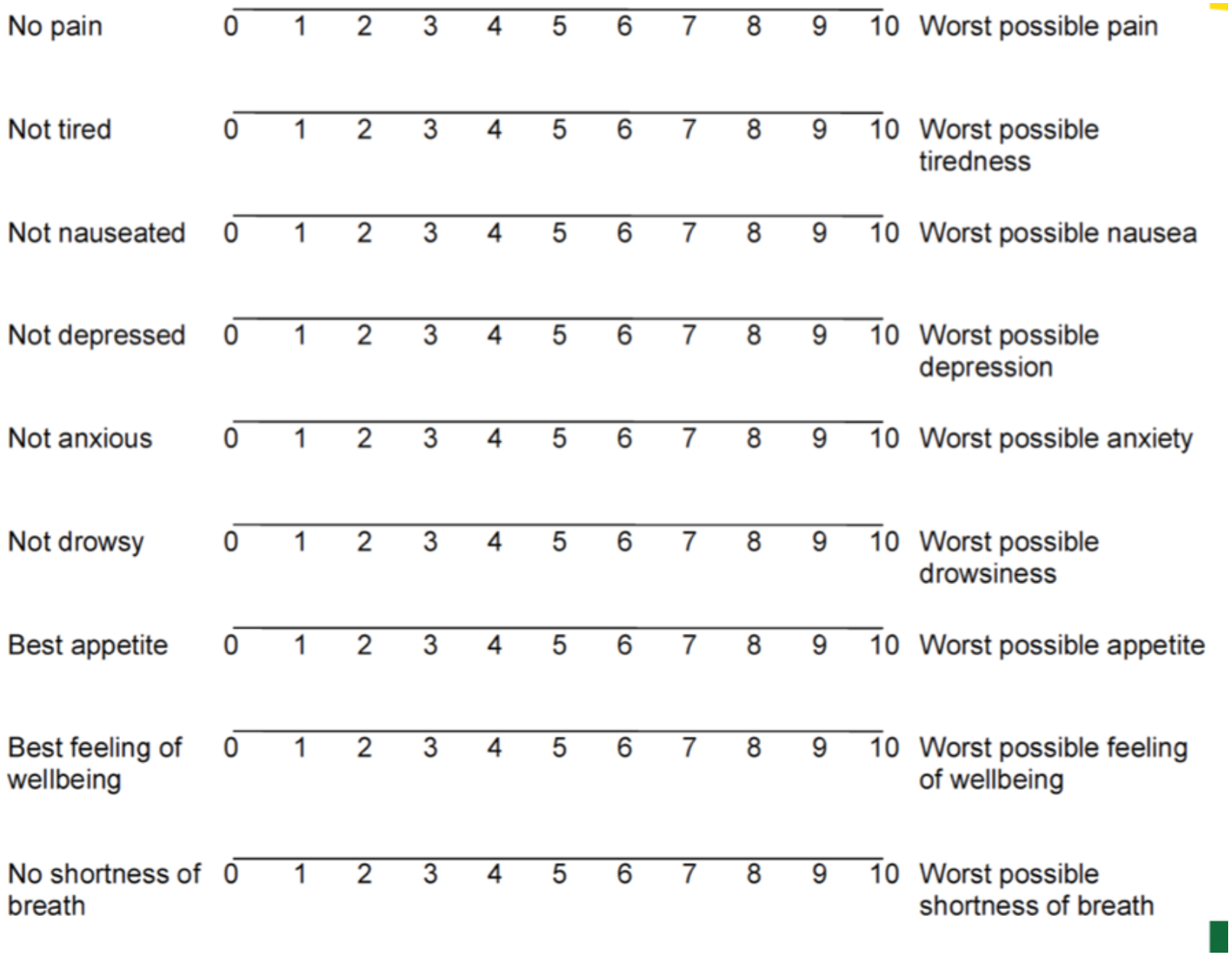
Case: Paul

- 2 years later, Paul is losing weight again (10 lb in 1 month) due to progressive dysphagia, fatigue.
- Despite being on modified diet, he takes over 1 hour to eat and does not finish meals
- He is Hoyer-lifted out of bed daily, and is no longer ambulatory even with assistance
- He has constipation despite a bowel routine and may go for 5 days without a BM, needing enema and bisacodyl supp
- He sleeps a lot and rarely talks. He tries to grab things in front of him.
- He complains of “pain in back, legs and shoulders”

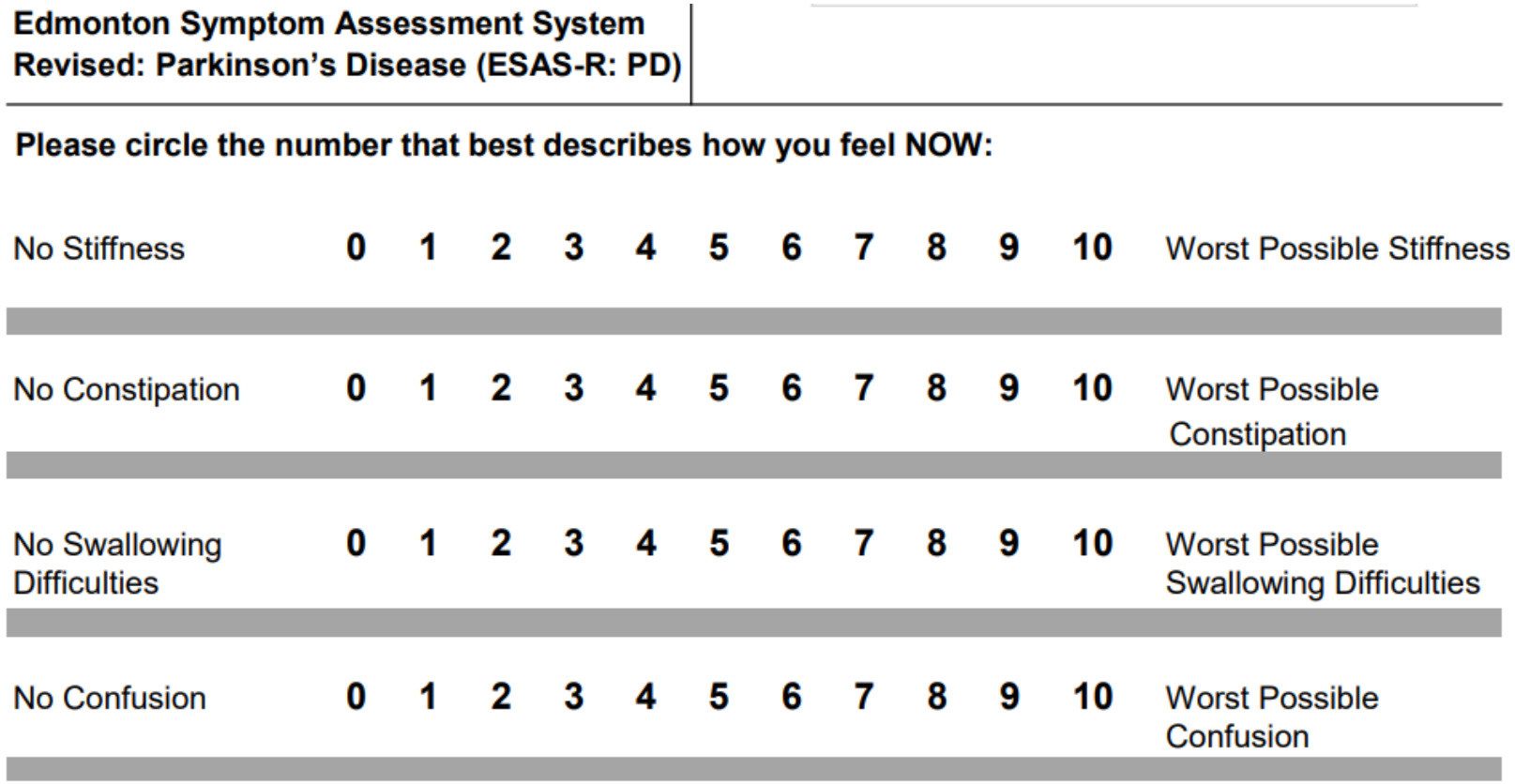
Assessment:

Hoehn and Yahr Stage 5 PD, Clinical Frailty Scale - 8

Edmonton Symptom Assessment Scale



ESAS-PD



Edmonton Symptom Assessment System Revised: Parkinson's Disease (ESAS-R: PD)

Please circle the number that best describes how you feel NOW:

No Stiffness	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Stiffness
No Constipation	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Constipation
No Swallowing Difficulties	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Swallowing Difficulties
No Confusion	**0**	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	Worst Possible Confusion

Miyasaki JM, Long J, Mancini D, et al. Palliative care for advanced Parkinson disease: an interdisciplinary clinic and new scale, the ESAS-PD. Parkinsonism Rel Disord. 2012;18:S6–9.

Results

- ESAS-PD scores improved from 56 to 40 ($p<0.0001$) with palliative care
- Most improved items were constipation, dysphagia, anxiety, pain and drowsiness.
- ESAS-PD scores were not significantly different from end stage metastatic cancer patients' ESAS scores (similar degree of suffering)

Palliative care in advanced parkinsonism is effective, improve QOL, symptoms. Palliative care should be available to patients with advanced parkinsonism as burden of suffering similar to end-stage cancer.

Miyasaki JM, Long J, Mancini D, et al. Palliative care for advanced Parkinson disease: an interdisciplinary clinic and new scale, the ESAS-PD. Parkinsonism Rel Disord. 2012;18:S6–9.

Neuropalliative Care – still largely an unmet need

- Even among established patients with Parkinson's disease in a quaternary center, the majority had never been offered palliative care or hospice service.
- Patients and caregivers want to be introduced to these concepts early on

(Ref: Kundrick et al. Adopting a palliative care mindset is an unmet need in Parkinson's disease *Clin Park and Rel Disord* Vol 9m 2023, 100206)

RESEARCH ARTICLE

Health Care Utilization in the Last Year of Life in Parkinson Disease and Other Neurodegenerative Movement Disorders

Erica D. McKenzie, MD*, Veronica A. Bruno, MD, MPH*, Andrew Fong, Pin Cai, Madalene Earp, Richard M. Camicioli, MD, Ingrid de Kock, MD, Daniela Buttenschoen, MD, Aynharan Sinnarajah, MD, MPH†, and Janis Miyasaki, MD, MEd†

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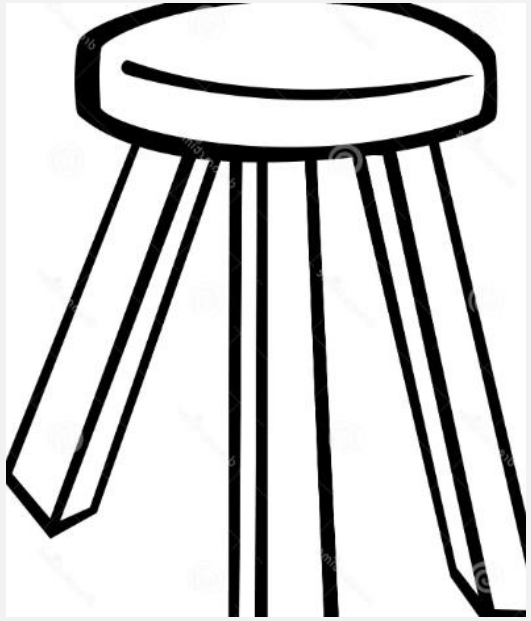
Neurology: Clinical Practice December 2022 vol. 12 no. 6 388-396 doi:10.1212/CPJ.0000000000200092

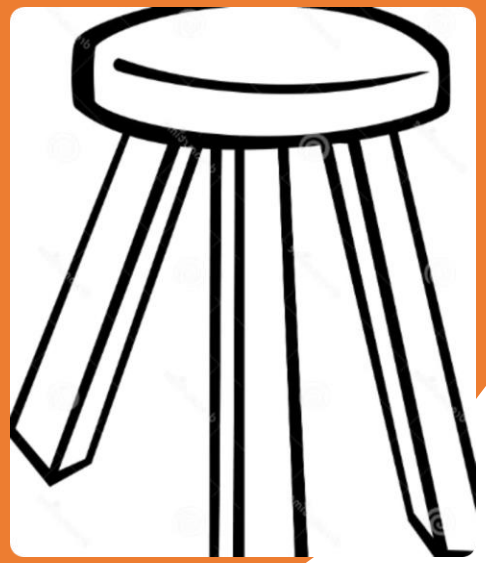
- 1439 people with Advanced PD and atypical parkinsonism
- 45.9% died in acute care hospital
- 36.3% in LTC
- 64% had more than 1 hospitalization
- 23% spent > 30 days in hospital
- 2.6% in ICU

Constipation – the 3-legged stool



- Texture
- Motility
- Core Strength

Constipation



- General: Fluids, fiber, exercise, stop culprit meds
- TEXTURE:
  - PEG, lactulose, fluids
  - NO PSYLLIUM – ineffective due to poor fluid intake and GI motility in older patients with PD
- MOTILITY (LOW):
  - Disease states – DM, PD/parkinsonism, sedentary
  - Drugs – opioids, anticholinergic, antipsychotic, antinauseants
  - stimulants should be prescribed more regularly (e.g., four times weekly, up to daily).

Constipation

- Adherence to bowel routine may be poor to “avoid accidents”
- Adhere to PEG 3350 8.5 to 17 gm daily + stimulants (senna or bisacodyl)
- May need enema or supp regularly (q2-3d) +/- disimpaction due to progressively diminished core strength
- AVOID psyllium and FIBER supplements – without adequate and motility – makes constipation worse

PAIN and Stiffness

- Often MSK, exacerbated by immobility
- Maintain reasonable regimen of levodopa – check by ensuring not too rigid on exam but more levodopa beyond this will NOT help
- *Assisted ROM exercises and stretches can help lessen pain, improve constipation and lessen rigidity*
- *Premed with acetaminophen may help with discomfort during exercise*

→ *Reduce chance of contractures and more pain*

Pain meds

- Acetaminophen 650 mg po tid
- Assess for neuropathic pain, dystonia – may consider Pregabalin as adjunct for pain and anxiety
- Tramacet, oxycodone *
- Hydromorph 0.5 – 1 mg po qid PRN
- If on tramacet/opioid, MUST HAVE STIMULANT LAXATIVE ordered

*Miyasaki J. Curr Neurol Neurosci Rep (2013) 13:367

Confusion/fatigue/anxiety

- Discuss with family their hopes and goals
- Lack of evidence but clinical experience recommendations:
  - Gradually reduce PD drugs (e.g. DA agonists, amantadine, MAO-B inh, entacapone) to arrive at simplified levodopa regimen
  - Continue antidepressants but may need lower doses
  - Melatonin and clonazepam helpful for vivid dreams/REM sleep disorder
  - If on memantine, can continue
  - If on cholinesterase inhibitor, reassess carefully if not eating and losing weight
  - Caffeine for fatigue
  - Spiritual support and team members e.g. OT and SW may be helpful in counseling and providing adjunctive therapies

Prognostic factors for death in PD

- Older age
- ***Weight loss***
- Multiple comorbidities
- ***Fractures***
- ***Infections – esp aspiration pneumonia***
- Dementia
- ***Dysphagia***

Table 2 Summary of predictors of mortality for Parkinson's and related disorders

Domain	Description	Assessment
Demographic and clinical markers	Age at onset/duration of disease	>61 years of age at onset
	Chronological age	78–85 years of age
	Sex	Male
	Body mass index (BMI)	Accelerated decrease in BMI for patients with PD (18.5–25 kg/m^2)
	Comorbid illness	Congestive heart failure, diabetes mellitus, pressure ulcers, cardiovascular disease
	Prescribing shift	Shift to fewer dopaminergic medications from previous visits (ie, ≤2)
Motor symptoms and global disability	Hoehn and Yahr Scale (H&Y)	H&Y stage increases (from stages 3–5 at first assessment)
	Postural instability gait disorder	Increase in scores from baseline as low as 1 unit on Tinetti balance and gait assessment and SPES/SCOPA
	Unified Parkinson's Disease Rating Scale (UPDRS)	Significant increases in overall UPDRS Score (≥10 point increase in total scale score over first assessment)
	Activities of daily living	Severe score (2 or less)
	Palliative Outcomes Scale (POS)	Upward trajectory of POS scores compared with first assessment
	Progressive Supranuclear Palsy Rating Scale (PSPRS)	Significant increases in PSPRS scores over 35
Falls and infections	Fracture risk	Fractures in previous 3–5 years with attention to fracture site (upper limb, lower limb, hip)
	History of infections	Pneumonia diagnosis
		Sepsis or urosepsis
Non-motor symptoms	Dementia/cognitive impairment	Diagnosis in medical record history using DSM classification; MMSE Score≤24; SCOPA-COG<23; severe cognition from CPS
	Visual hallucinations; vision problems	UPDRS I question 2 with a score≥2; SCOPA-PC: presence in past month of hallucinations, illusions, paranoid ideation or altered dream phenomena; diagnosis if rapid eye movement sleep behaviour disorder; >2 medical claims for psychosis
	Dysphagia	UPDRS II question 3 with a score≥2 and correlated with clinical assessment; survey of caretakers
	Neurologic bladder disturbances	Incontinence and incomplete bladder emptying

Akbar, U. et al (2021). Prognostic predictors relevant to end-of-life palliative care in Parkinson's disease and related disorders: a systematic review. *Journal of Neurology, Neurosurgery & Psychiatry*, *92*(6), 629–636.

Palliate in LTC with an interdisciplinary team where possible to avoid acute care hospital use and more suffering

NEVER STOP LEVODOPA COLD TURKEY – COULD CAUSE NEUROLEPTIC MALIGNANT SYNDROME

NPO options for rigidity

Rectal Levodopa (1:1 conversion from oral)

Preparation of rectal suspension:

- Crush 10 tablets of levodopa-carbidopa 100/25
- Mix with 10 mL of 50% water + 50% glycerin mixture

  (2 tablets = 2mL)
- Lower pH to 2.3-2.4 using 1 g of citric acid
- Administer levodopa-carbidopa suspension (1 tablet per mL) using a 3-mL syringe attached to a 6-cm catheter
- Store between 2°C-8°C in an amber bottle
- Use within 24 hours Shake well before use

Canadian Family Physician 2001 (47) 112-3

NPO Options for rigidity

Rotigotine Transdermal patch 2, 4, 6, 8 mg

Conversion:

- Calculate daily levodopa dose – may reduce by 10- 20% esp in palliative situation
- Entacapone – increases the individual dose by 20%
- CR – absorbed only 50-70%
- Multiply “reduced” total daily levodopa dose by 0.033 to get Patch dose

Rotigotine is a Dopamine Agonist – thus risk of hallucinations. Keep dose on low end

Case: Paul
He is sleeping all day, not alert enough to eat or take po

MEDICATIONS:

- Levocarb 100/25 2.5 tab 5 times daily
- Rasagiline 0.5 mg daily --> D/C
- Quetiapine 12.5 mg hs --> D/C
- Lactulose 30 cc po daily --> D/C
- Senokot liquid po hs -> Bisacodyl supp q2-3d
- Donepezil 5 mg cc breakfast --> D/C

DOSE CALCULATION for dopa:

From Levocarb 250 mg x 5 = 1250 mg

From Rasagiline 0.5 mg = ?

TOTAL = 1250 mg per day

Very sleepy, bedbound, may reduce by 10 – 20%

Target = 1000 mg per day --> taper gently

Options:

1. Levodopa rectal 250 mg qid (preferred)

2. Rotigotine patch =levodopa dose x 0.033 = 33 mg/24 h --> low ball it --> 24 mg daily (16 mg + 8 mg patch)

3. Taper further as near death - levodopa rectal tid after 3 days and patch dose down gradually

SUMMARY

Advanced PD/ parkinsonism - Role of the LTC physician

- Recognize and help manage motor and non-motor complications
- Early discussion re: GoC and manage expectations
- Balance motor Sx control with mental clarity and QOL
- Recognize signs of deterioration, e.g. weight loss, dysphagia, infections
- Palliate pain, stiffness, constipation, anxiety