

PD Advanced Stages: Cognitive Changes and Palliative Care

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- No disclosures or conflicts of interest

Outline

- The PD Hydra
- Cognitive changes and dementia
- Mortality
- What is palliative care and how can it help people with PD
- Advanced Care Directives

AN
ESSAY
ON THE
SHAKING PALSY.

BY
JAMES PARKINSON,
MEMBER OF THE ROYAL COLLEGE OF SURGEONS.

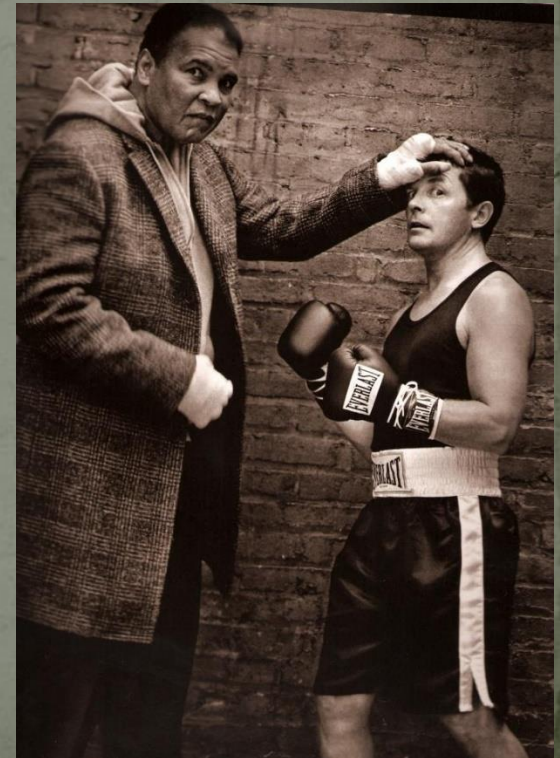
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Cardinal Features of PD

- Shaking → Tremor
- Palsy → Bradykinesia
- Difficulty with gait and falls → Postural Instability
- ??? → Rigidity



Non Motor Features of PD



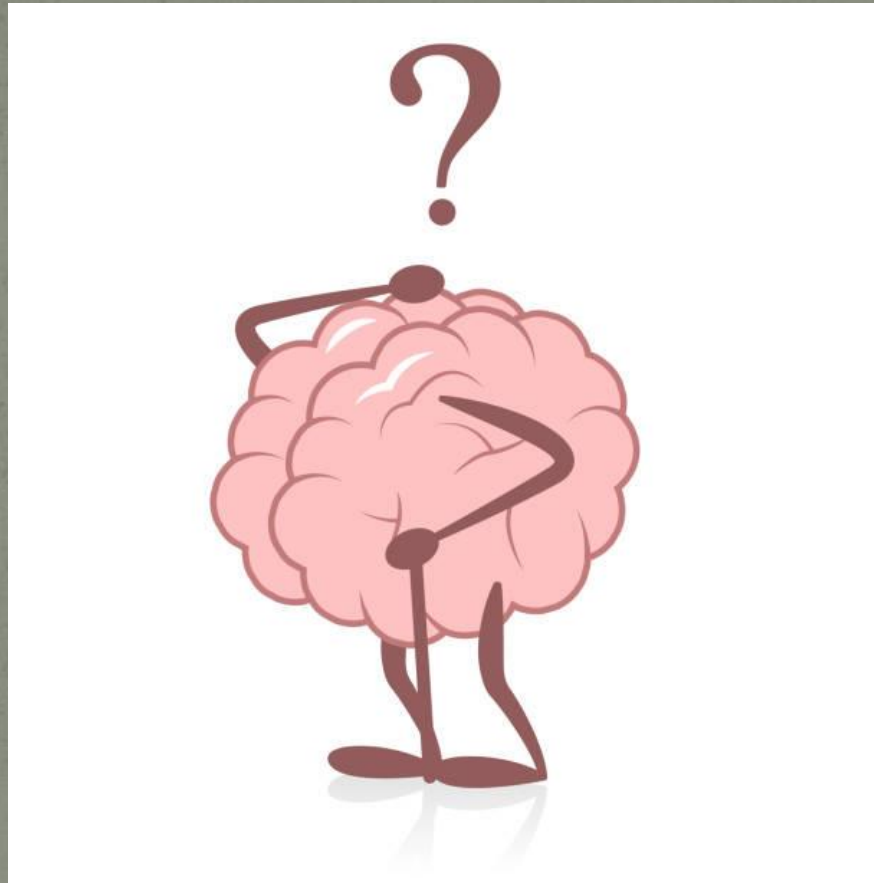
Drooling
Olfactory and taste dysfunction
Choking and swallowing difficulties
Nausea and vomiting
Constipation
Fecal incontinence
Bladder dysfunction
Pain
Weight loss & weight gain
Cognitive dysfunction and Dementia
Hallucinations
Depression
Anxiety
Apathy
Sexual dysfunction
Orthostatic hypotension
Excessive daytime sleepiness
Insomnia
REM sleep behaviour disorder
Restless leg syndrome
Leg swelling
Excessive sweating
Diplopia and visual abnormalities
Delusions
Impulse control disorders

But wait... there's more!

- Caregiver strain
- Spiritual distress
- Transportation
- Relationships with Friends and Family
- Planning for the future
- ...



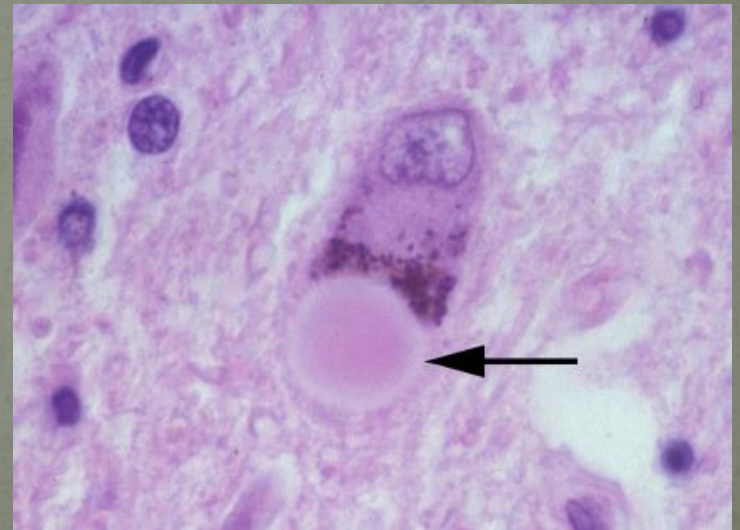
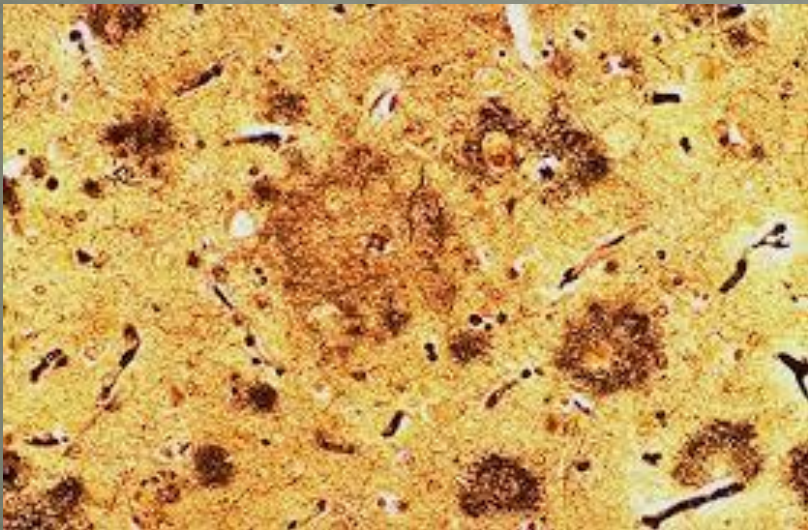
Cognitive Impairment



Terms

- Pseudo-dementia
 - subjective cognitive impairment caused by a medical or psychological problem
- Mild Cognitive Impairment
 - subjective cognitive impairment
 - lower than normal score on formal cognitive test
 - no obvious cause
- Dementia – impaired daily function
 - Alzheimer's
 - Lewy Body Dementia
 - Vascular
 - Mixed
 - others

- Diagnosis of the specific type of dementia is difficult without brain tissue sample
- Often it doesn't really matter



Incidence

- Within three years of diagnosis
 - 25% converted to MCI
 - 20% converted to dementia while 28% reverted back to a state of normal cognitive function
 - To me this indicates a large amount of pseudo-dementia
 - 2% converted to dementia

Prevalence

Movement Disorders
Vol. 23, No. 6, 2008, pp. 837–844
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The Sydney Multicenter Study of Parkinson's Disease: The Inevitability of Dementia at 20 years

Mariese A. Hely, MBBS,^{1*} Wayne G.J. Reid, PhD,¹ Michael A. Adena, PhD, ASTAT,²
Glenda M. Halliday, PhD,³ and John G.L. Morris, MD¹

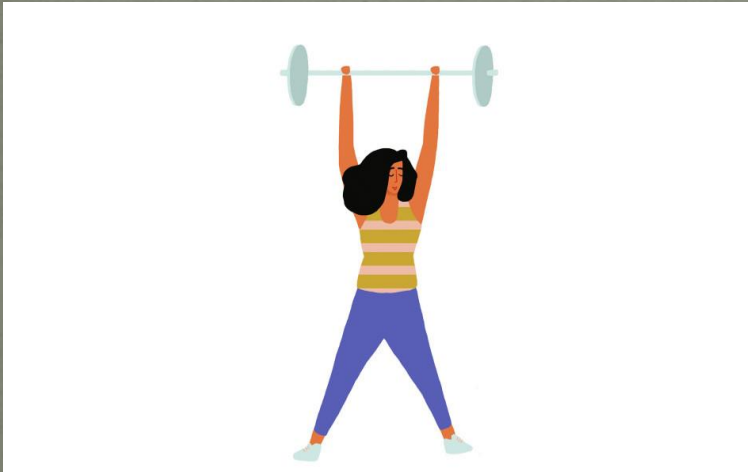
- Dementia is present in 83%
- 17 people with dementia had postmortems. 8 had diffuse Lewy bodies as the only cause of dementia, while others had mixed neuropathology.

Risk Factors

- Atypical parkinsonism
 - PSP, MSA, DLB, Vascular parkinsonism
- Hallucinations
- Greater motor impairment
- Longer duration of illness
- Male gender
- Older age

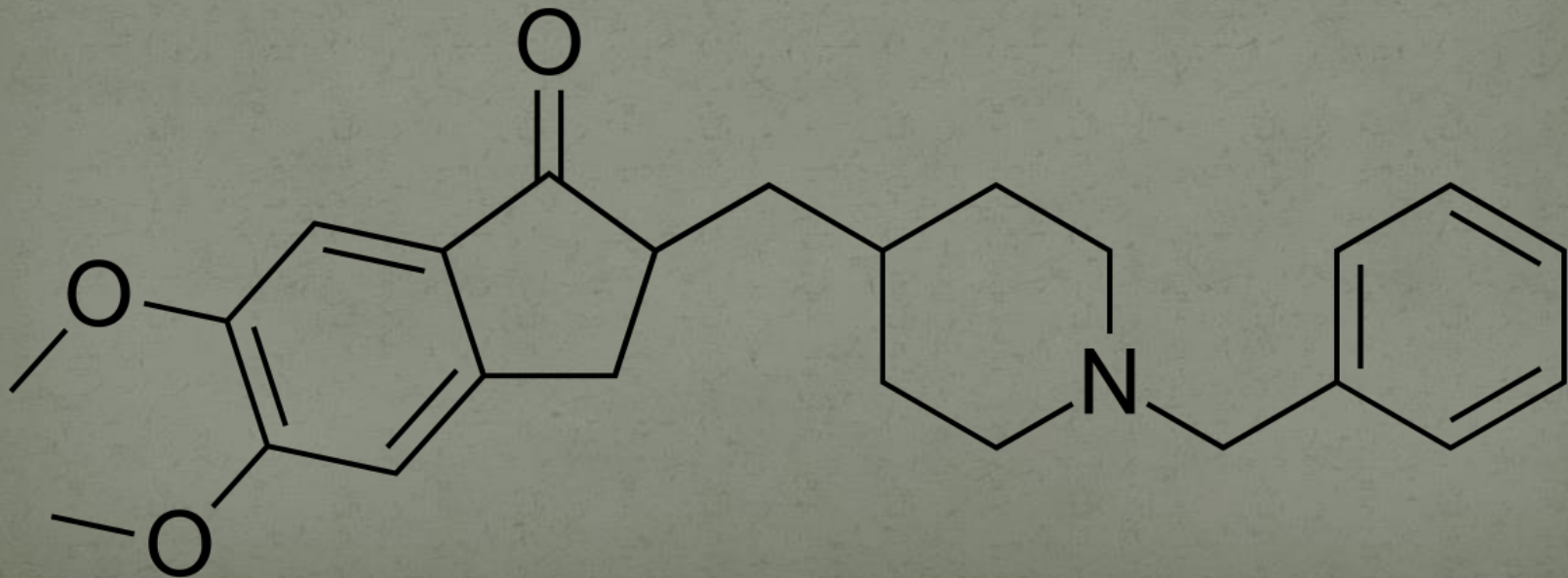
Prevention

- Exercise
- Social and mental activity
- Managing other medical issues



Management - Medications

- Cholinesterase inhibitors (donepezil, rivastigmine)
- NMDA receptor antagonist (memantine)
- Quetiapine, clozapine, pimavanserin (USA)



Management - Lifestyle

- Happy and Safe
 - Home safety
 - Driving safety
 - Enjoy life
- Caregiver support
- Advanced care planning documents



When to give up license?

- four-fold increase in MVCs per 1,000 miles driven per week in 3 years prior to dementia diagnosis



End of Life

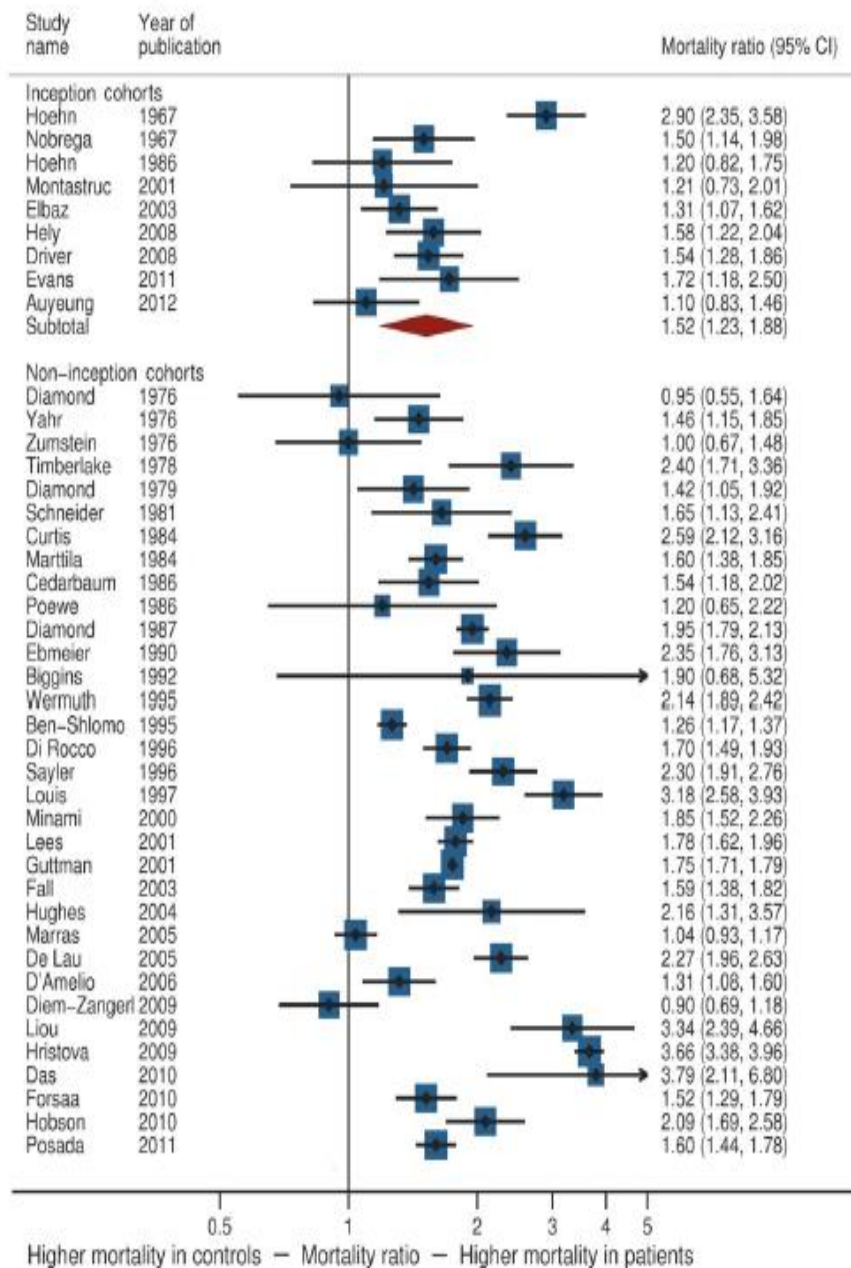


Mortality in Parkinson's Disease: A Systematic Review and Meta-analysis

Angus D. Macleod, MRCP,^{1*} Kate S.M. Taylor, MD,² and Carl E. Counsell, MD¹

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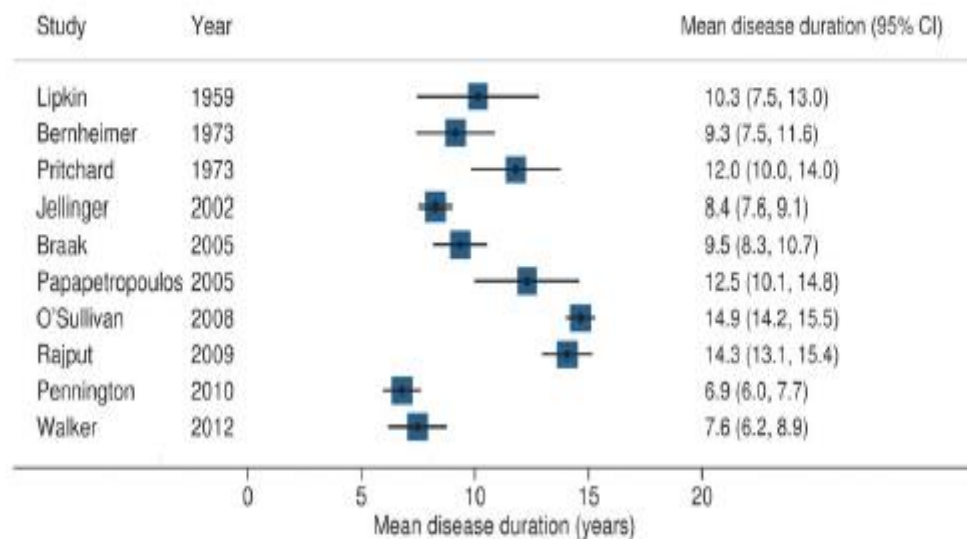


FIG. 4. Meta-analysis of time from disease onset or diagnosis to death in a retrospective series of deceased patients using a DerSimonian and Laird random effects model. The I^2 heterogeneity statistic is 97.4%; a pooled estimate is therefore not presented. [Color figure can be viewed in the online issue, which is available at wileyonlinelibrary.com.]

- median age at death was 83 years (range 47-101 years)



Tuck et al 2015

- Although patients presenting with idiopathic parkinsonism have reduced survival, the survival is highly dependent on the type and characteristics of the parkinsonian disorder. Patients with Parkinson disease presenting with normal cognitive function seem to have a largely normal life expectancy

Deep Breath

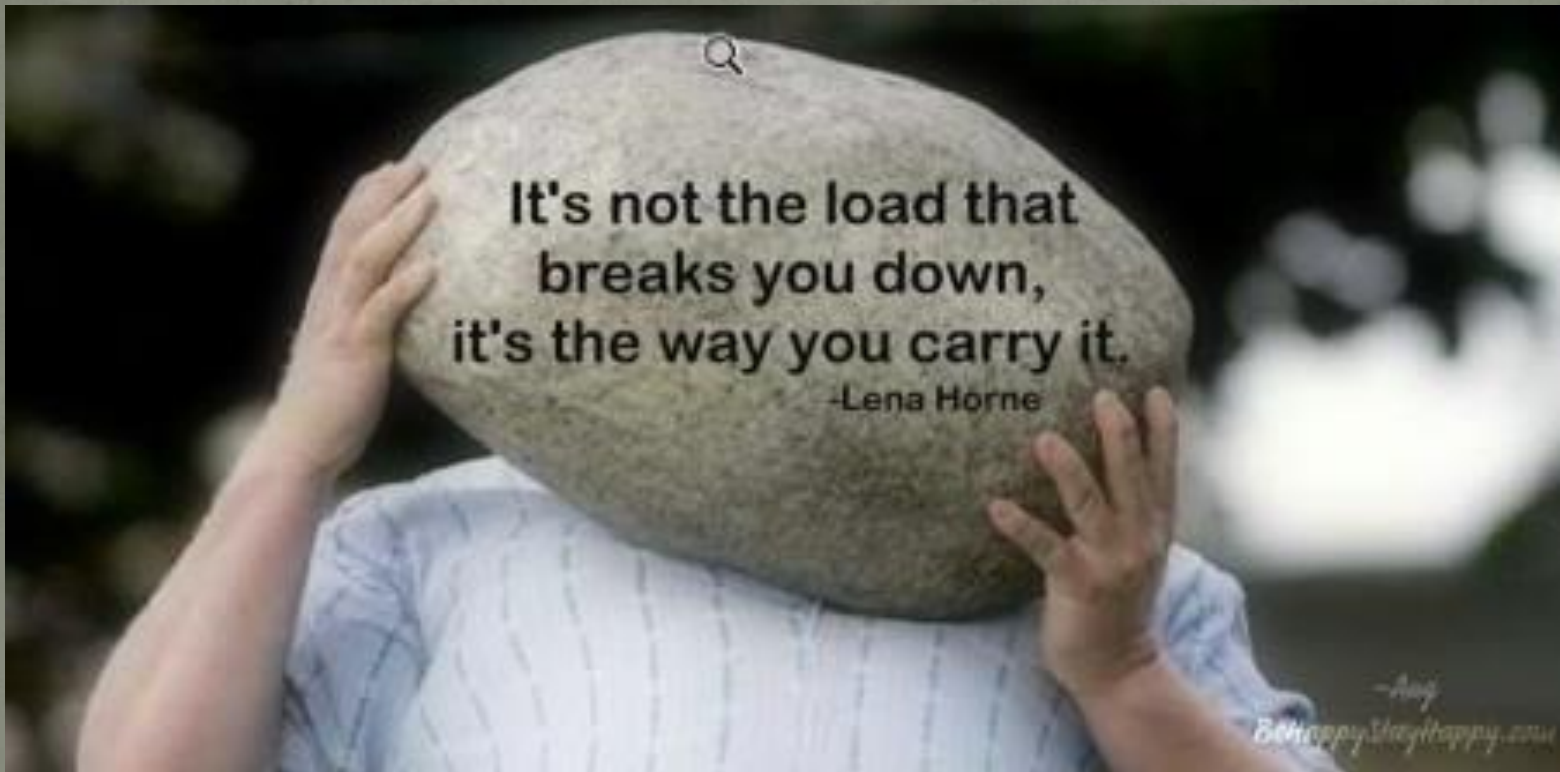
MOTIVATIONALBUCK.COM



OVERWHELMED

SURE, I CAN HANDLE THE LOAD. NO PROBLEM.

- “The early stages, including problems of motor complications from medications are largely treatable. It is the later stages... that are virtually untreatable at present.”

A photograph of a person from the chest up, wearing a light blue and white striped shirt. They are carrying a large, smooth, grey rock on their back, with their hands resting on the sides of the rock. The background is blurred, showing green foliage and a bright light source. The image is framed by a dark, textured border.

**It's not the load that
breaks you down,
it's the way you carry it.**

-Lena Horne

*-Amy
BethappyStayHappy.com*

- PD management requires a team approach involving patients, families, caregivers and numerous clinicians
- Even with your help your neurologist cannot do it all

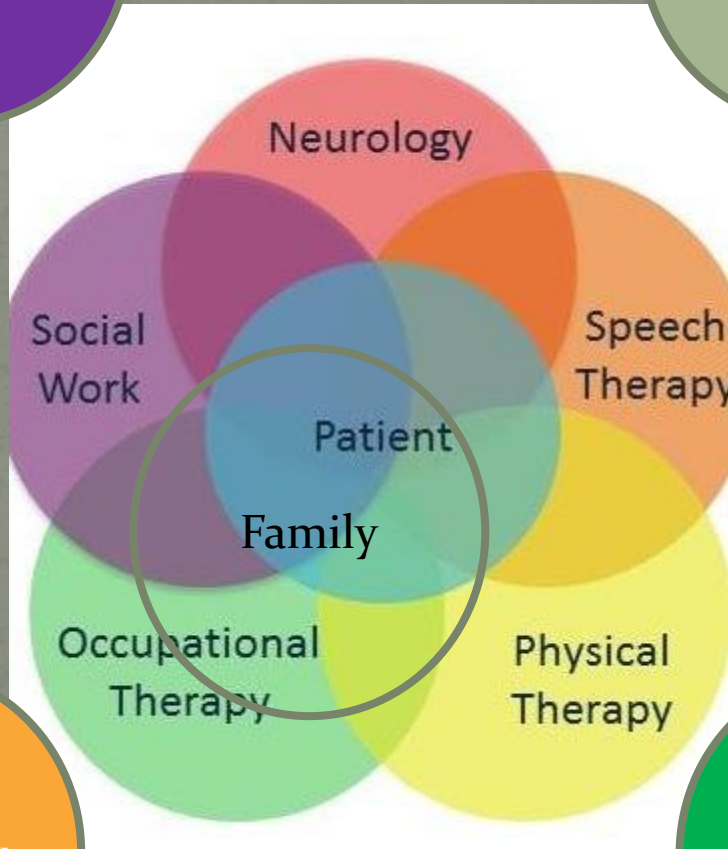


Palliative Care for PD?

- “Palliative care is an approach that improves the **quality of life** of patients and their **families** facing the problem 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.**”
- **Multidisciplinary**



World Health
Organization



Goals of Palliative Care

- Improve pain and symptom control
- Improve satisfaction for patients and caregivers
- Improve quality of life and functional status
- Reduce hospital admissions
- Reduce fragmentation and be more efficient with time

- Services vary by region
- PD Pal Care clinic in Edmonton
- Likely are Pal Care doctors in your area
 - Referral of neurology patients is not common, but is growing

- “The best way to predict the future is to create it.”

Advanced Care Documents

- Will
- Medical Advanced Directive
- Health Care Power of Attorney
- MOST



Life-sustaining treatment orders, location of death and co-morbid conditions in decedents with Parkinson's disease

Keiran K. Tuck^a, Dana M. Zive^b, Terri A. Schmidt^{b,c}, Julie Carter^a, John Nutt^a, Erik K. Fromme^{c,*}

Place of Death and POLST Use

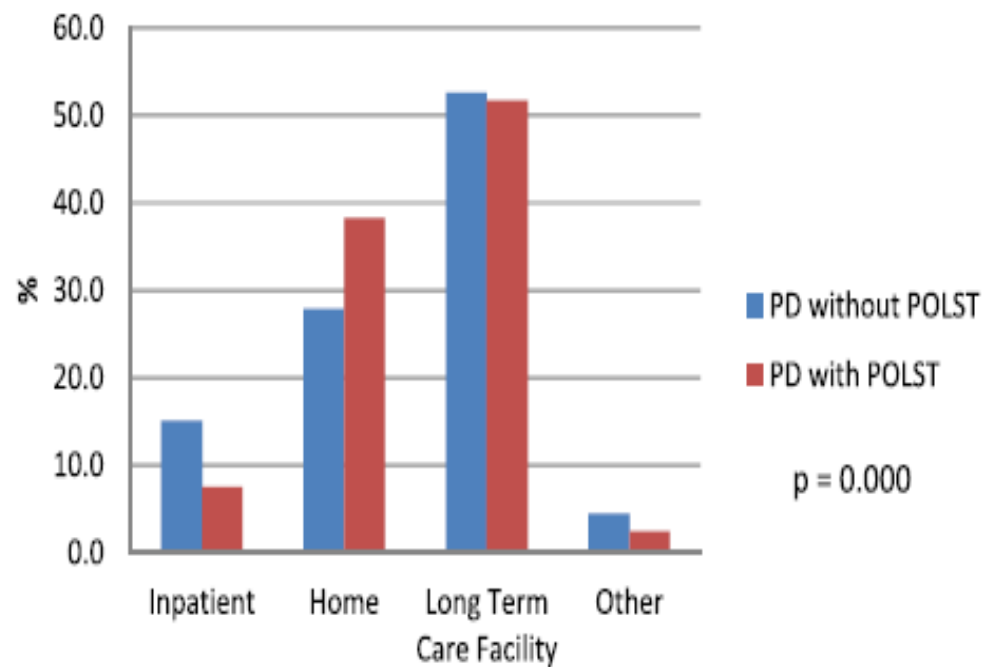
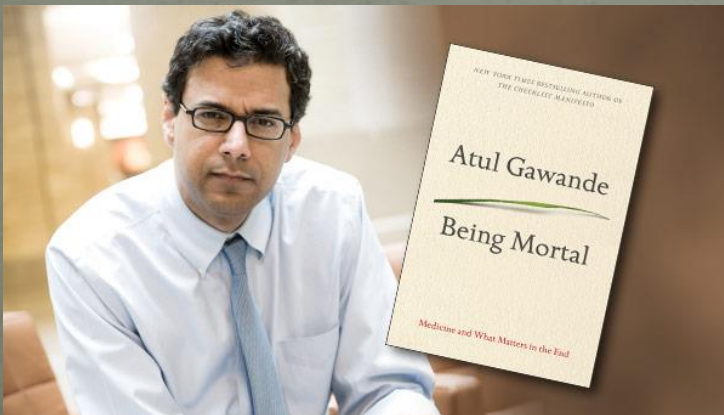


Fig. 1. Place of death and POLST use.

- Again, the best time to do something is too early instead of too late

“We’ve been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive.”



Take home points

- PD affects numerous aspects of life, not just your movement
- One of the possible complications is cognitive impairment
- Exercise!!!
- Palliative care is not just end of life care, but can also help you cope with the numerous complications of PD
- Plan for the future

Thank you to Parkinson's BC

- And to all it's members

Questions?

