



University of Colorado **Anschutz Medical Campus**

The Unique Palliative Care Needs of Those Living with Serious Neurologic Disease: Neuropalliative Care

Christina L Vaughan, MD, MHS
Chief, Section of Neuropalliative Care
Associate Professor, Neurology & Medicine



OVERVIEW

Brief review of palliative care in Neurology



5 Unique Palliative Care Features of Neurological Disease



2 cases

- Chronic neurodegenerative disease

AAN POSITION STATEMENT

“Many patients with neurologic disease die after long illnesses during which a neurologist acts as the principal or consulting physician. Therefore, it is imperative that neurologists understand, and learn to apply, the principles of palliative medicine.”

- Ethics and Humanities Subsection, American Academy of Neurology, 1996



Special Article

Neurology 1996;46:870-872

Palliative care in neurology

The American Academy of Neurology Ethics and Humanities Subcommittee

Palliative care is defined by the World Health Organization (WHO) as

The active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achieve-

care permits the optimal management of psychological and social problems and attention to the spiritual needs of the patient.

Palliative care and the goals of medicine. The goals of medicine are many and include cure of dis-

SINCE 1996...

- Few if any hours of palliative care in neurology education curriculum at most residencies
- Expansion of palliative care from cancer to heart failure, lung disease, and ESRD
- Emerging interest in palliative care for many neurologic conditions including ALS, dementia, stroke, and Parkinson disease (PD)
- Increasing number of neurologists that are double-boarded in HPM

<https://www.neuropalliativecare.org/>



ABOUT MEMBERSHIP MEETINGS RESOURCES EDUCATION RESEARCH CAREER CENTER FOR MEMBERS



Language Translation Option: Download the Google Translate extension* in the Chrome Web Store to translate the INPCS website into another language. [Click here](#) to learn more.

**Available in the Chrome Browser only*

A world where high quality, person-centered care is available to all people and families affected by neurologic illness.

WHO WE ARE

INPCS is about human connections in neurology, breaking silos between traditional medical walls, and keeping the person ill at the center of all of the efforts. The overarching purpose of the International Neuropalliative Care Society (INPCS) is to foster the growth of this field by creating a community. Activities of INPCS include building professional networks, supporting research, developing educational materials and opportunities, creating guidelines for clinical practice, and advocacy.

The New York Times

Dying in the Neurosurgical I.C.U.

In cases of brain death or neurologically devastating injury, poor communication can make painful situations even harder.

By Joseph Stern, M.D.

Published Jan. 14, 2020 Updated Jan. 20, 2020

MULTIPLE SCLEROSIS

Palliative Care for MS: What It Is, When It's Helpful

This approach to MS care focuses on quality of life and may be beneficial at any stage of the disease.

By Quinn Phillips Medically Reviewed by Samuel Mackenzie, MD, PhD
Last Updated: August 5, 2019

March 4, 2021

Standard guidance needed for palliative care referral in dementia, experts find

Alicia Lasek

<https://www.mcknights.com/news/clinical-news/standard-guidance-needed-for-palliative-care-referral-in-dementia-experts-find/>

Neurology > Parkinson's Disease

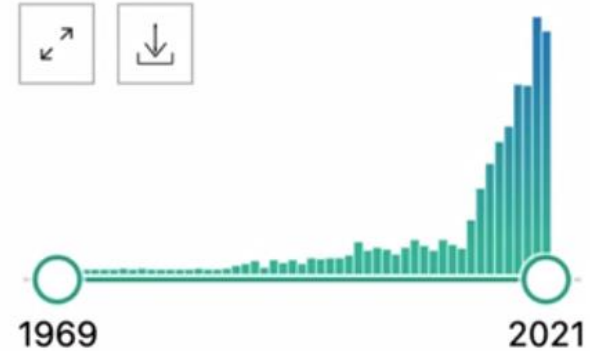
Parkinson's Patients See Benefit With Early Palliative Care

— Palliative model aims to improve quality of life at early disease stages

by Judy George, Senior Staff Writer, MedPage Today February 10, 2020

We are witnessing exponential growth in clinical care, education and research.

RESULTS BY YEAR



Presidential Address: Taking Flight – a Vision for the Future of Neuropalliative Care: B Kluger, 11/4/2021

Parkinson's Foundation Launches Palliative Care Program Across U.S. Centers of Excellence

Funds awarded by the Patient-Centered Outcomes Research Institute

MIAMI & NEW YORK – August 11, 2020 – The [Parkinson's Foundation](#) is partnering with the University of Rochester Medical Center, a Parkinson's Foundation Center of Excellence, to launch an initiative to make palliative care a standard practice across all Centers of Excellence in the U.S. The award was granted to the University of Rochester Medical Center by the Patient-Centered Outcomes Research Institute

Usual Neurologic Chronic Care -vs- Palliative Care

Usual Care	Palliative Care
Focuses on disease-related medical symptoms	Focuses on <i>total pain</i> of serious illness (physical, psychosocial, spiritual, practical challenges)
Focuses on improving physical health	Focuses on improving overall well-being and reducing suffering
Seeks to prolong life	Affirms and values life, while planning for inevitable decline and end of life
Focuses on patient	Focuses on patient and family/carepartners
Focuses on enhancing <u>quantity</u> of life	Focuses on enhancing <u>quality</u> of life

Unmet Palliative Care Needs in Typical Neurology Models of Care

Poor communication and inadequate psychosocial support at time of diagnosis for most conditions

Under-recognition and under-treatment of symptoms

Low rates of advance care planning discussions and completion of advance directives

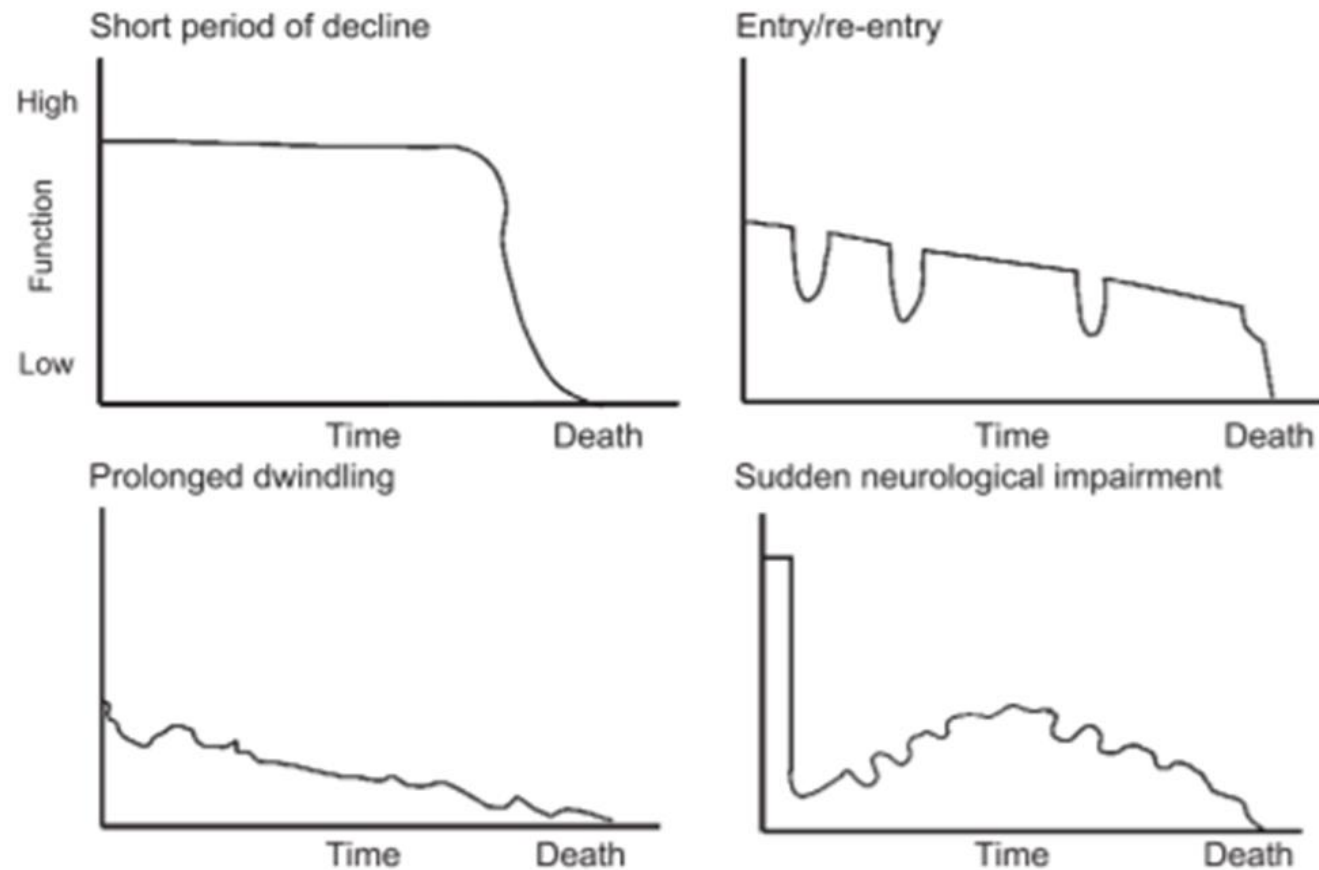
Lack of standardized approach to goals of care discussions

Lack of systematic approaches to carepartner support, psychosocial issues, or spiritual wellbeing

Low rates of hospice use (4-20% for most disorders) and high rates of hospital deaths (~50%)

1. Illness Trajectories

Figure 1 Trajectories to death and disability by neurologic disease



- Frameworks: anticipate and respond
- Uniqueness of **severe acute brain injury**: can have early death, chronic stage of recovery, survive for long periods + significant disability, shift into any trajectory

2. Symptom Profiles

Cognitive and behavioral deficits

Cosmetic effects

Burden of invisible symptoms (ex: fatigue)

Fear of dementia

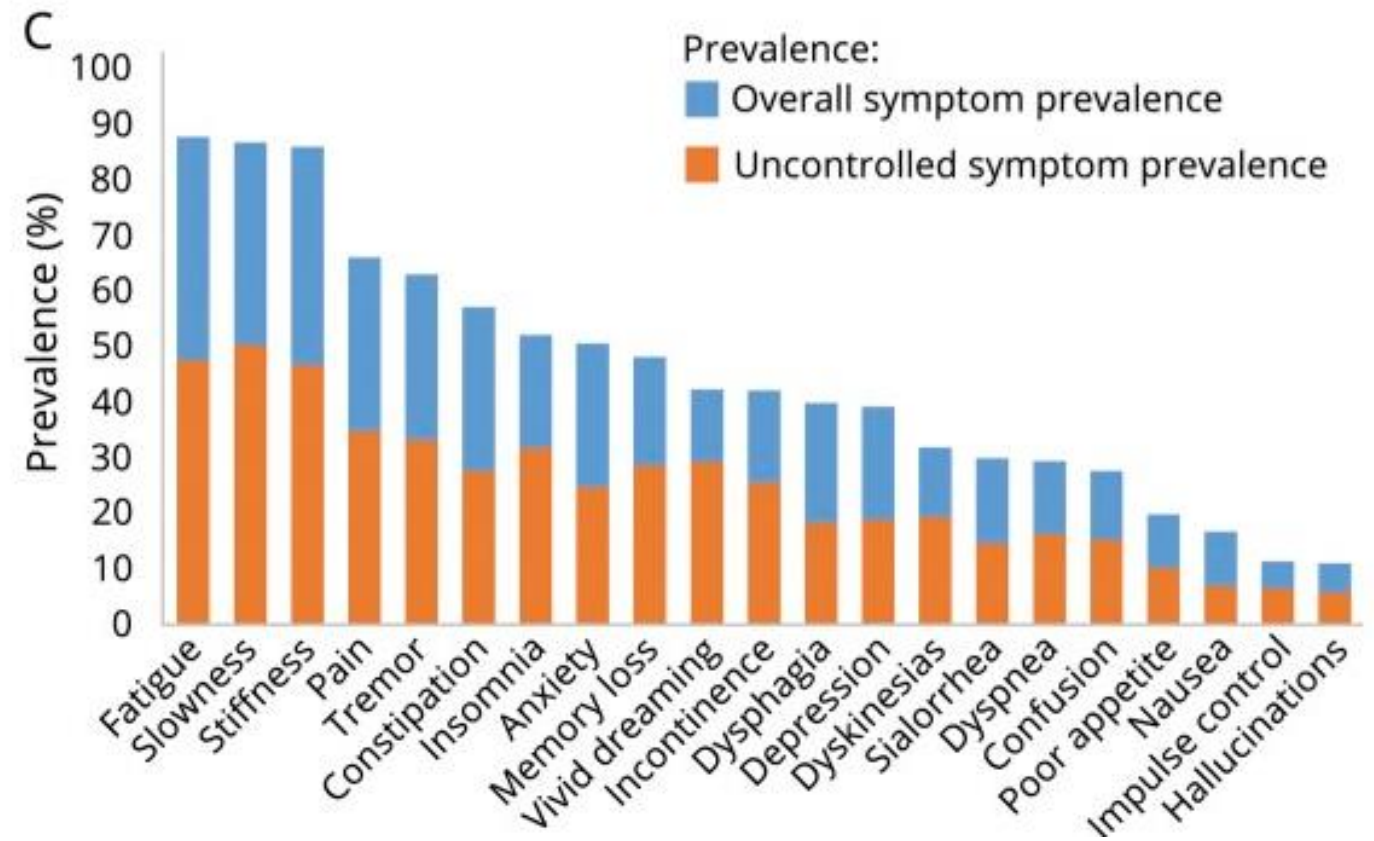
Social isolation and loneliness

Communication difficulties

Social stigma

Uniqueness of brain cancer (vs other cancers):
seizures, cognitive decline, headaches, other focal neurologic deficits

Symptom burden among individuals with Parkinson disease: A national survey



Symptoms Can Interfere with Communication

Abulia

Aphasia

Anosognosia

Cognitive impairment

- Limited or no capacity

Dysarthria/anarthria

Pseudobulbar affect

+

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○

3. Existential and Psychological Suffering

- Loss of personhood
 - *“Losing my husband 1 inch at a time”*
 - Severe acute brain injury ~ dramatic loss, causing family to wonder *“is he still in there?”*
- Patients with MND have more demoralization, hopelessness, SI than those with metastatic cancer
- Cancer often felt to be “extrinsic” or something to be fought or removed
 - in contrast- neurologic illness often felt as more intrinsic or even a personal failure (forgetfulness, misbehavior, clumsiness)

4. Caregiver Needs

Profound level of physical and cognitive disabilities

Psychiatric and behavioral issues

Often long duration of caregiving needs

Cognitive impairment ~unable to make decisions → "surrogate decision making"

Behavioral problems ~high caregiver burden; SNFs often ill-equipped (young pts with HD, MS, TBI)



“Neurologists are used to uncertainty—
diagnoses are frequently challenging, too
often there are limited treatment options,
and unpredictable prognoses are our bread
and butter.”

5. Uncertainty: Diagnostic and Prognostic

- Ubiquitous within many neurological illnesses
- Uncertainty about what the future holds can deprive patients/families of a **sense of control** → stress and emotional turmoil
- Best case, worst case and most likely case scenarios
- Prognostic tools (do not predict QOL):
 - Glasgow Coma Scale
 - Hunt and Hess grade
 - Intracerebral hemorrhage score
 - NIH Stroke Scale
 - FUNC score
- Estimating outcome in neurologic illness is more challenging than in the oncology population

Treatment preferences

- Since the course of many neurological diseases leads to significant dysfunction, many require particularly timely and effective planning regarding
 - GOC
 - substitute decision-makers
 - ACP
 - EOL decisions
- Acutely honoring treatment preferences is complicated:
 - long, progressive course of many of these diseases
 - potential for individuals to incorrectly predict their QOL and what they would want in a future health state

Case

“Total pain”

Chronic neurodegenerative disease

- 71M, retired welder, PD dx 2005 s/p b/l STN DBS 2015
- Developed axial weakness and muscle wasting; dx: axial myopathy. Genetic testing: pathogenic variant in CAPN3 and SQSTM1 - of unknown significance
- Worsening bradykinesia and imbalance, severe knee pain
- MCI: MoCA 25/30
- RBD, nOH, illusions, depression

	7a	11a	3p	7p	1030p
Rytary 195 mg	2	2	2	2	
Duloxetine 60 mg	1				
Midodrine 5 mg	1		1		
Lorazepam 0.5 mg					1

“What it’s
like living
with PD”

GOC conversation

- Prior to PD: welder who worked on pipelines x20-30 yrs- he enjoyed this. Fishing in streams and rivers, camping with his wife, took trips around the SW, did 4-wheeling. *"Never occurred to me that there would be a time when I wouldn't work - I thought I'd work until I die."*
- Joy: seeks activities that give him a sense of purpose (running for the Board of the HOA). Spending time with grandchildren "is what he lives for."
- Worries: finances for wife if he dies first
- Hopes: to continue to walk, to maintain cognition, to focus on QOL

Management

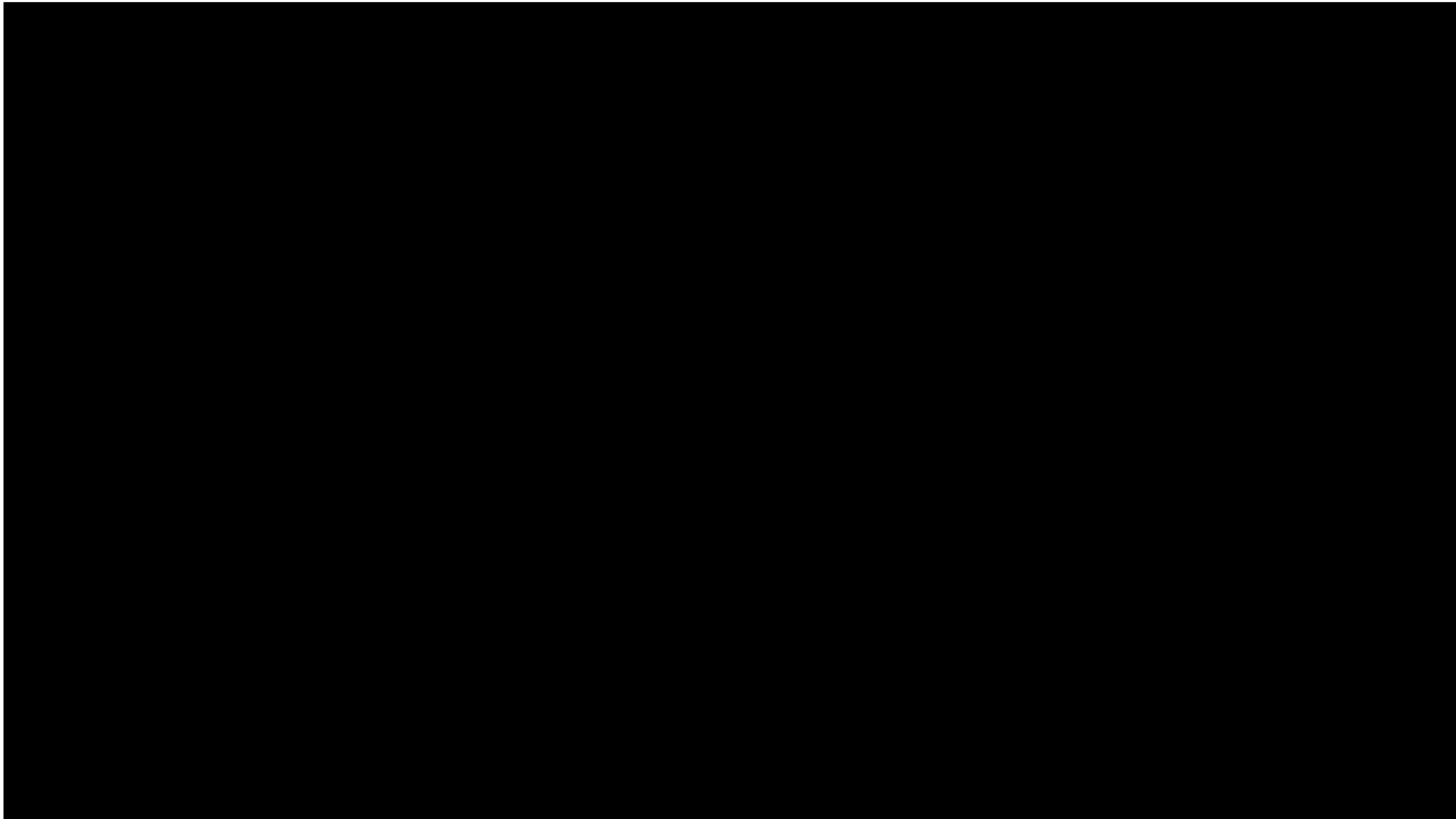
- FOG, worsening imbalance: PT, Nitro walker
- Depression: duloxetine, at-home counseling, Chaplain meetings
- Apathy: socialization: “Wiser Mind”
- RBD: benzodiazepine
- Knee pain (severe tricompartmental OA): US-guided injection
lidocaine, DepoMedrol
- Medication compliance: alarm
- Caregiver burnout: socialization, respite care (SW), time away,
Chaplain meetings, support group

Explains what QOL is



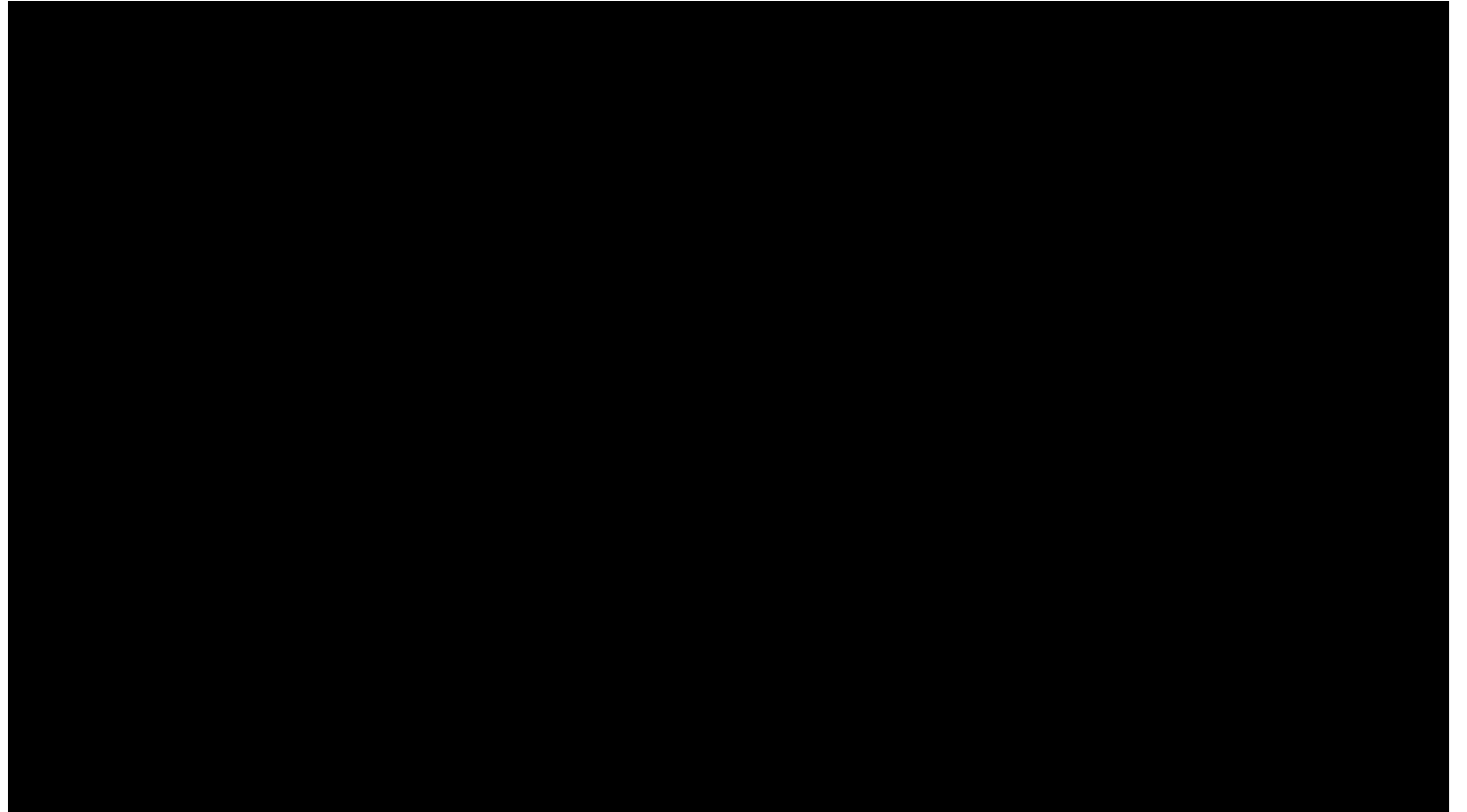
Case

Value-based goals, medical decision-making:
Chronic neurodegenerative disease



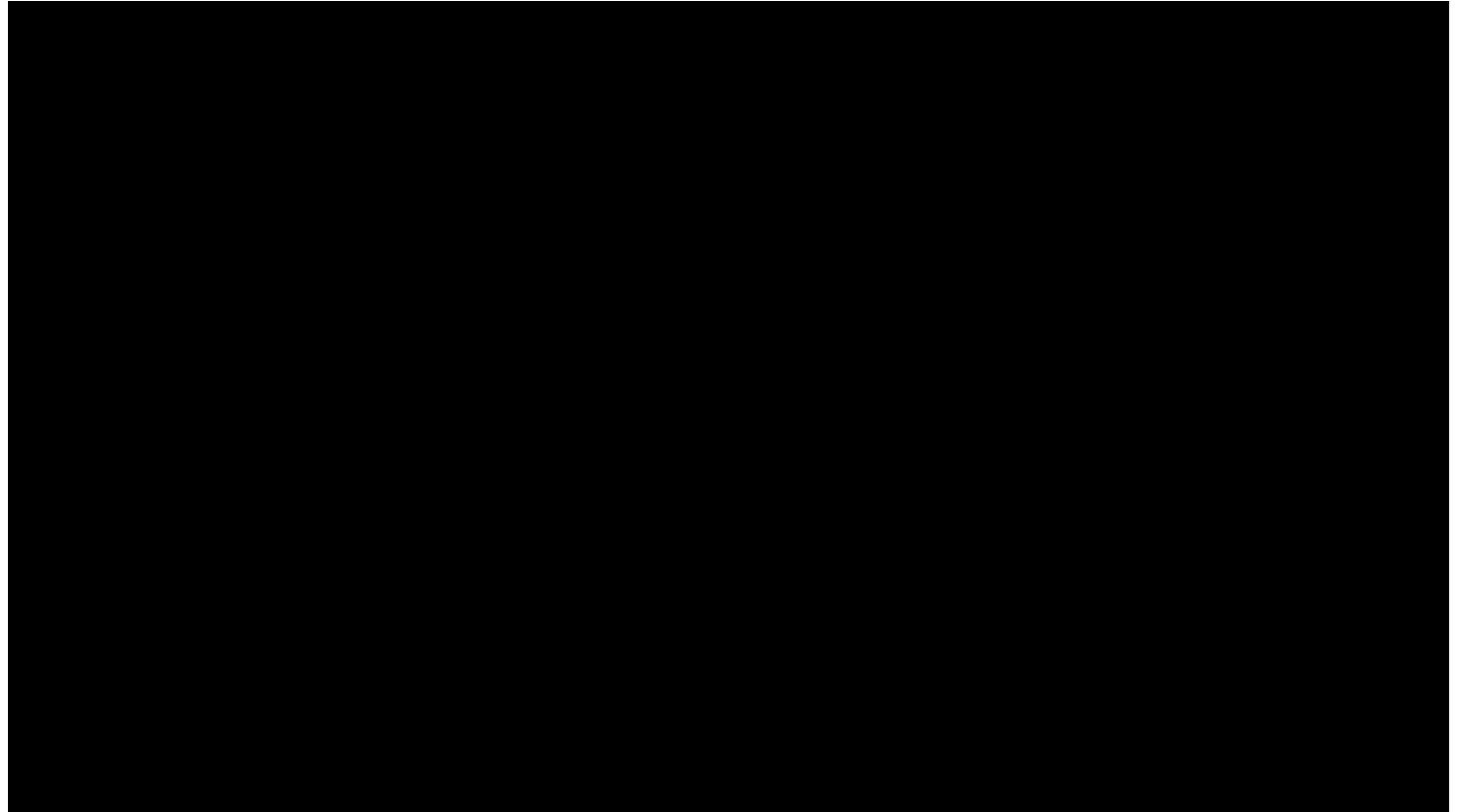
Living with PD

- 79M sx PD in 2006, dx 2008
- Duopa pump 2017
- Afib s/p ablation, stent
- b/l hips and knees replaced, L5/S1 fusion
- 2018: documented concerns re: “development of dementia” prompted by “mild degree of cognitive fncn”
- 7/2020 goals: “to continue to be active, **to never be in a wheelchair**”



Falls, sequelae, surgery?

- 2 major falls: R-femur fx 2019 and L-femur fx 2020
 - Severe pain (referred to knees)
 - Essentially wheelchair-bound
 - b/l loose femoral components and failed bipolar hip arthroplasties
- Proposed surgery: revise both hips: R-side and ~4 mos later, then L
 - Goals: to walk again with walker and reduce pain ~75%



PD and surgery

- Increased risk of nosocomial morbidity
 - Dysphagia 50-80% PWP → aspiration PNA, malnutrition
 - PWP: ↓ respiratory fncn (bradykinesia and insufficient resp muscle mvmt) → PNA risk
 - ↑ risk: falls, UTI
 - Medication administration: ontime, Duopa/oral meds

Table 1 General Recommendations

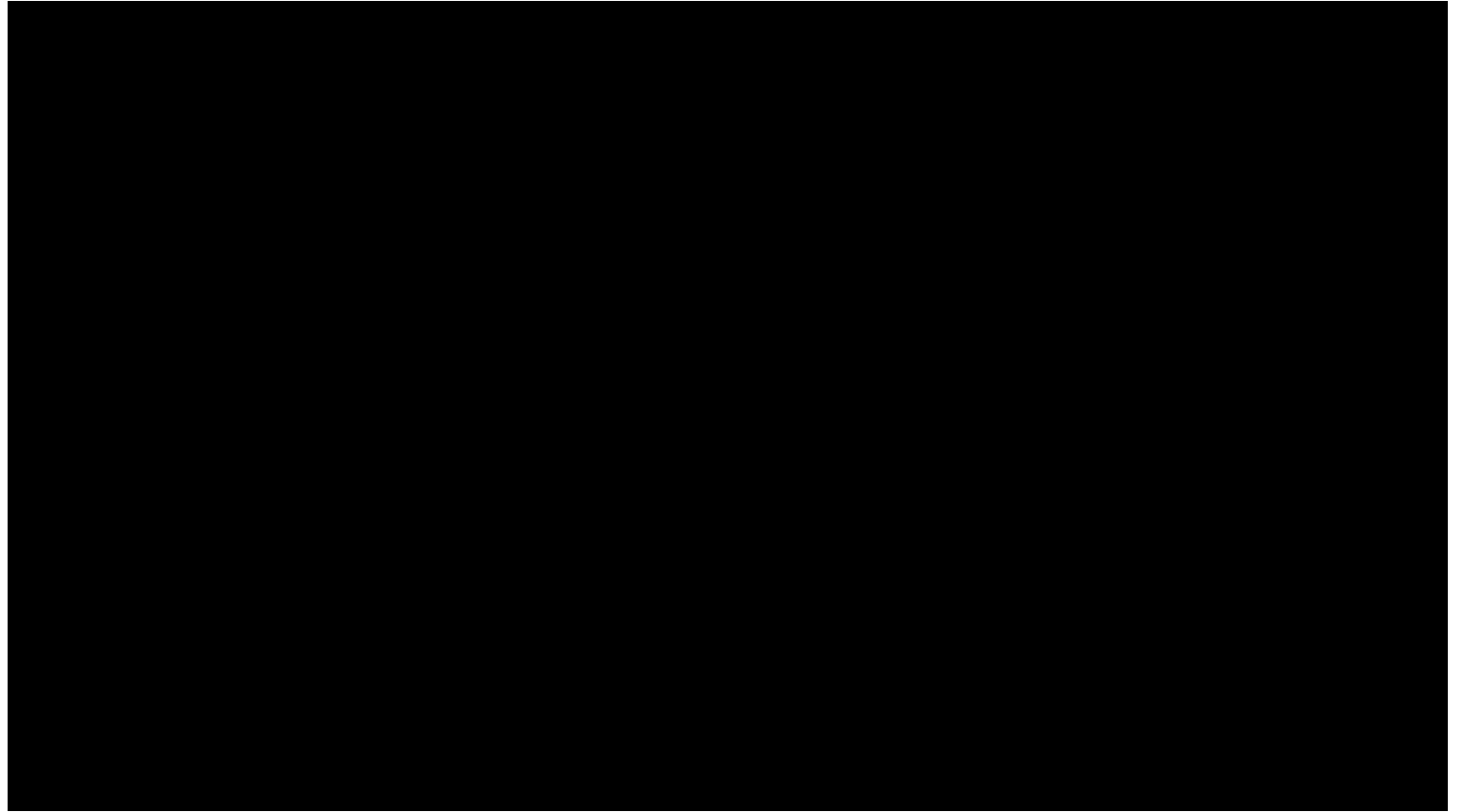
Issue	Complication
Difficulty maintaining Parkinson's disease medication schedule	Exacerbation of Parkinson's disease, increased rigidity → increased fall risk, and decreased mobilization and associated complications Parkinsonism hyperpyrexia syndrome
Dysphagia, sialorrhea, dysmotility	Aspiration, pneumonia Constipation
Deep brain stimulator	Damaging leads during cauterization Controversial contraindication of MRI
General anesthesia	Certain medications might exacerbate Parkinson's disease symptoms or interact with Parkinson's disease medications.
Postoperative nausea	Certain anti-emetics can worsen/cause extrapyramidal symptoms.
Postoperative pain	Immobility Interactions between analgesic and anti-Parkinson's disease medications
Fluctuations in blood pressure	Orthostatic hypotension Hypertension
Cognitive impairment	Agitation and hallucinations Falls
Urinary retention	Urinary tract infection
Rigidity/immobility	Contractures Pressure ulcers General deconditioning

MAO-B monoamine oxidase-B; MRI = magnetic resonance imaging; NPO = non

Post-operative Cognitive Dysfunction

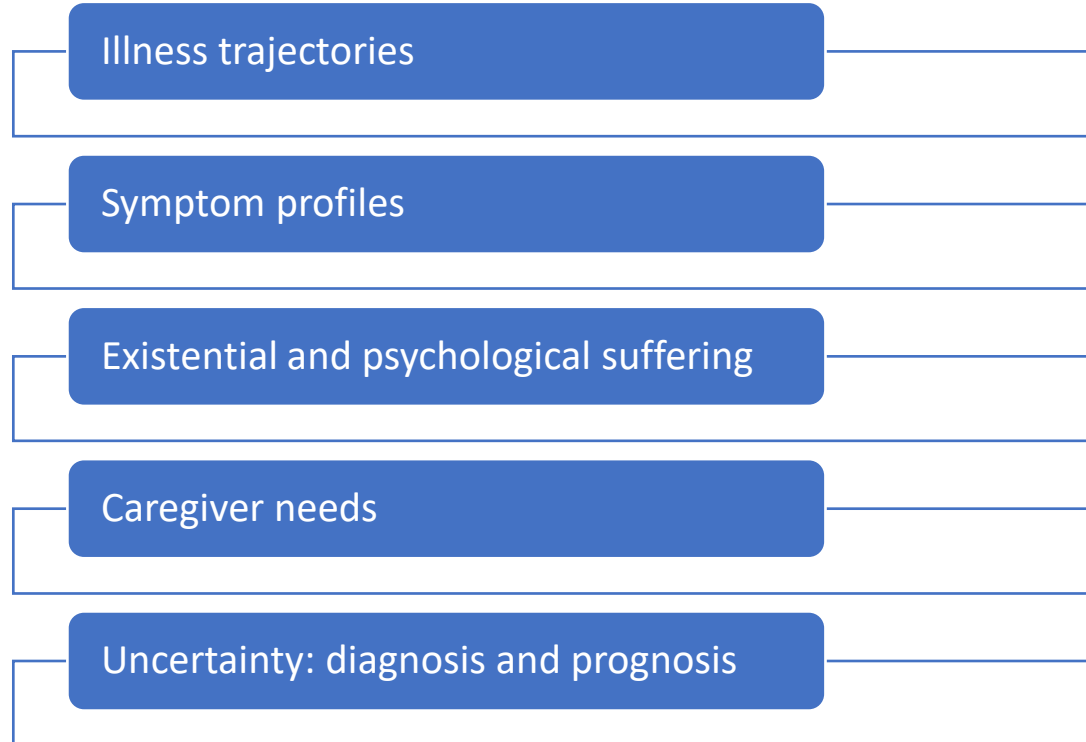
- POCD: post-op memory and/or thinking problems corroborated by neuropsychological testing
- pilot study to examine post-op cognitive decline in PWP (2015) undergoing orthopedic surgery
 - 80% of PD surgery sample experienced cognitive decline greater than that of the healthy surgery and non-surgery peers
 - processing speed and inhibitory functions

Outcome



Summary: Palliative care needs of neurologic populations

Unique Features



Palliative approach

- Addressing the “total pain” of the multitude of effects
- Exploration of value-based goals aids in decision-making



Thank You