

Department of Neurology
 SCHOOL OF MEDICINE
 UNIVERSITY OF COLORADO
 ANSCHUTZ MEDICAL CAMPUS

History of Palliative Care in Parkinson disease

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 March 16, 2023



Roadmap



1. History of Palliative Care
2. Neurology and Palliative Care
3. Original Neuropalliative clinics: focus on PD
4. Parkinson's Foundation and Palliative Care
5. Current state

- 1967: Saunders opened St Christopher's Hospice in London
- 1974: 1st hospice in the US in Branford, CT
- 1974: Dr Mount, surgical oncologist from McGill Univ coined "palliative care"
- 1988: Academy of Hospice Physicians → American Academy of Hospice and Palliative Care (AAHPM): 1996
- 1990: The WHO recognized "palliative care" as a distinct specialty
- 1996: American Academy of Neurology Position Statement
- 2006: ABMS and ACGME recognized "hospice and palliative care" as its own specialty
- 2007: Miyasaki et al: Palliative Care Program for PD in Toronto, CAN
- 2013: Kluger: Neuropalliative care clinic: University of Colorado
- 2015, 2016: Parkinson's Foundation sponsored 2 international PD + palliative care working groups
- 2020: Parkinson's Foundation: Palliative care program across 33 Centers of Excellence
- 2021: International Neuropalliative Care Society (INPCS) 1st annual meeting



Dame Cicely Saunders

- "founder" of the hospice movement
- Founded 1st modern hospice (1967)

"There was nothing more that could be done..."

"Palliative care"

Pallium ~ cloak
 To palliate is to cloak, or cover up, the symptoms of an illness without curing it. This meaning grew into the idea of alleviating or reducing suffering.



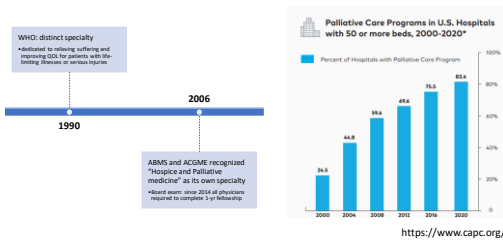
Dr. Balfour Mount, O.C., O.Q

"What has surprised me is how little palliative care has to do with death. The death part is almost irrelevant. Our focus isn't on dying. Our focus is on quality of life."



"There is so much more to be done..."

Palliative medicine as a field



AAN Position Statement: 1996

Special Article Neurology 1996;47(7):873

Palliative care in neurology

The American Academy of Neurology Editors and Nominations Subcommittee

Many patients with neurologic diseases 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.

Original neuropalliative clinics in N America



- **2007:** J Miyasaki et al - Palliative Care Program for PD and Related Disorders at Toronto Western Hospital
 - MovDis neurologist
 - Palliative care physician
 - Wound care nurse
 - Spiritual counselor
 - Care coordinator
 - **New scale: the ESAS-PD**
 - assessment of late-stage PD symptoms
 - **Unmet needs in PD - not receiving enough info and support from health-care system**
 - Felt "alone"
 - More info about diagnosis and prognosis
- Glinz S, Miyasaki J. Palliative stage Parkinson's disease: patient and family experiences of health-care services. *Palliat Med*. 2020.
 • Miyasaki JM et al. Palliative care for advanced Parkinson disease: an interdisciplinary clinic and new scale, the ESAS-PD. *Parkinsonism Relat Disord*. 2012.

Original neuropalliative clinics in N America



- **2013:** B Kluger – University of Colorado: "Improving Quality of Care, Outcomes and Cost in Neurologic Disease through an Interdisciplinary Outpatient Palliative Care Clinic"
- **Funding:** NIH/NIA; PCORI; PDF
- **2016:** NIH/NINR - "More than a movement disorder: Applying palliative care to Parkinson's disease"
- **Clinic began as ½-day per month, expanded over 4 yrs → 4 days/wk**
 - MovDis neurologist
 - Palliative care physician (initially)
 - Spiritual counselor
 - Social worker (from local PD organization)
 - Nurse
 - Eventually: physician assistant, additional physician, volunteers

The Parkinson's Fdn Commitment

- 2015, 2016: PF sponsored 2 international PD + palliative care working groups, including PwP and carepartners:
 - to summarize current state of the evidence
 - to highlight lessons learned from palliative care in other illnesses
 - to set research priorities



Kluger BM et al. Palliative care and Parkinson's disease: meeting summary and recommendations for clinical research. *Parkinsonism Relat Disord* 2017.

International Neuropalliative Care Society

- **MISSION:** To raise standards of care for all people affected by neurologic illness.
- **Members:** physicians/clinicians, IDT members, researchers, patients, carepartners
- **3rd annual meeting:** September 12-15, 2023, in Minneapolis, MN

In summary...

- It took many pioneers to:
 - Develop the field of Palliative Medicine
 - Initiate and expand palliative care services
 - Recognize the need for palliative care in chronic diagnoses other than cancer
 - To identify and recognize the unique palliative care needs of PwP and carepartners
 - To create innovative neuropalliative care clinics
 - Establish the new field of Neuropalliative care with its own international society
 - Develop research programs and obtain finding to demonstrate efficacy and value

