Palliative Care Town Hall

Megan Dini, Senior Coordinator, Clinical Affairs
Parkinson’s Foundation

Better Lives. Together.

Palliative Care Town Hall:

Collaboration and Partnership with Hospice and Palliative Care

Christina Vaughan, MD, MHS
University of Colorado, Anschutz Medical Campus

June 7, 2023

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Overview

Parkinson's Foundation

- WHAT defines hospice
- WHERE/HOW are Americans dying
- WHEN are people with PD eligible for hospice
- WHY neurology involvement is important for people living with PD: opportunities for collaboration

Hospice: *What*

Parkinson's Foundation

- "Founder" of hospice movement
- Founded 1st modern hospice (1967)
- "There was nothing more that could be done…"
- **"There is so much more to be done."**

Dame Cicely Saunders

A **team-based** system of care

intended to **empower** a person and their family/community

to live well until the **natural end of life**

in their chosen location.

Hospice: *What*

Parkinson's Foundation

- Support and care for persons in the last phases of an incurable disease
- Help the patient live as fully and as comfortably as possible
- Dying process is a part of the normal process of living
- **Affirms life**; neither hastens nor postpones death

Image Source: NHPCO Facts and Figures on Hospice Care, 2015

*Availability depends on geography

Hospice philosophy statement-NHPCO: National Hospice and Palliative Care Organization

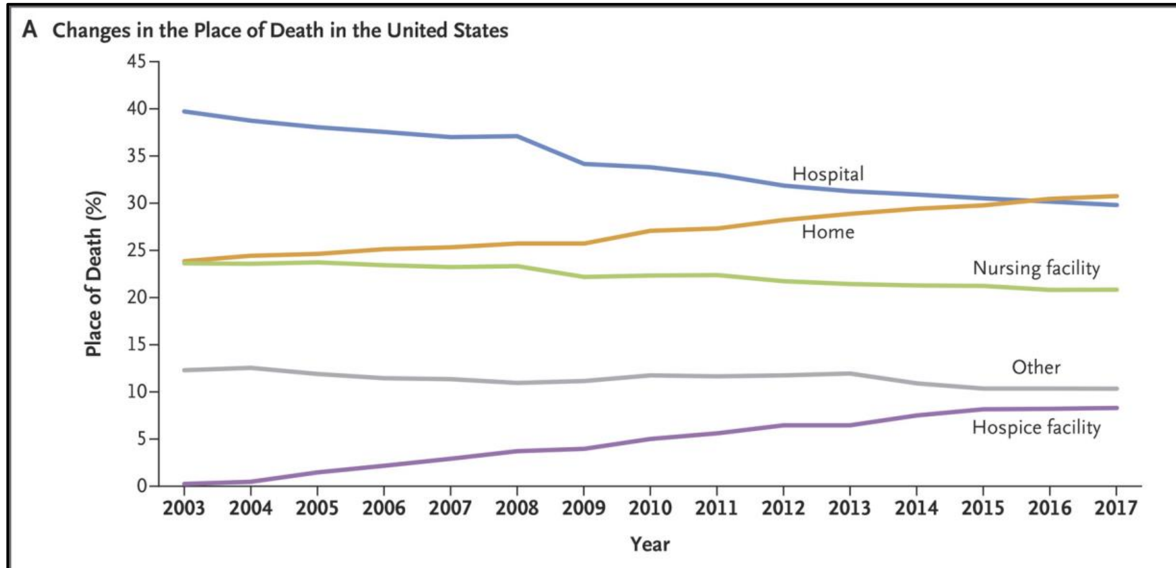
Hospice: *Where*

Parkinson's Foundation

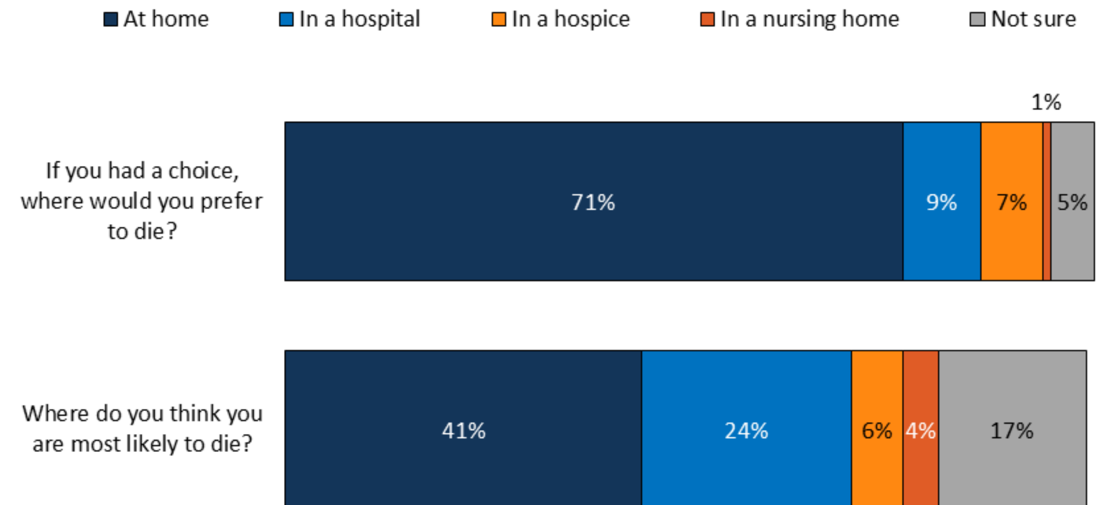
- Majority of hospice patients in own home or home of a loved one
  - "Home" may also be broadly construed to include: nursing homes, assisted living centers, hospitals…wherever the patient considers to be home
- Home coverage
  - 100% covered, not 24/7 care in the home
  - DME
  - Phone and emergency care
- Inpatient
  - 100% covered if patient meets criteria, 24/7 care in a hospice facility
  - "GI"= general inpatient
  - Active, uncontrolled and acute symptoms
  - LOS 3-5 days
- Inpatient in a nursing home
  - Room and board out of pocket, 24/7 care

Where are Americans dying?

Parkinson's Foundation

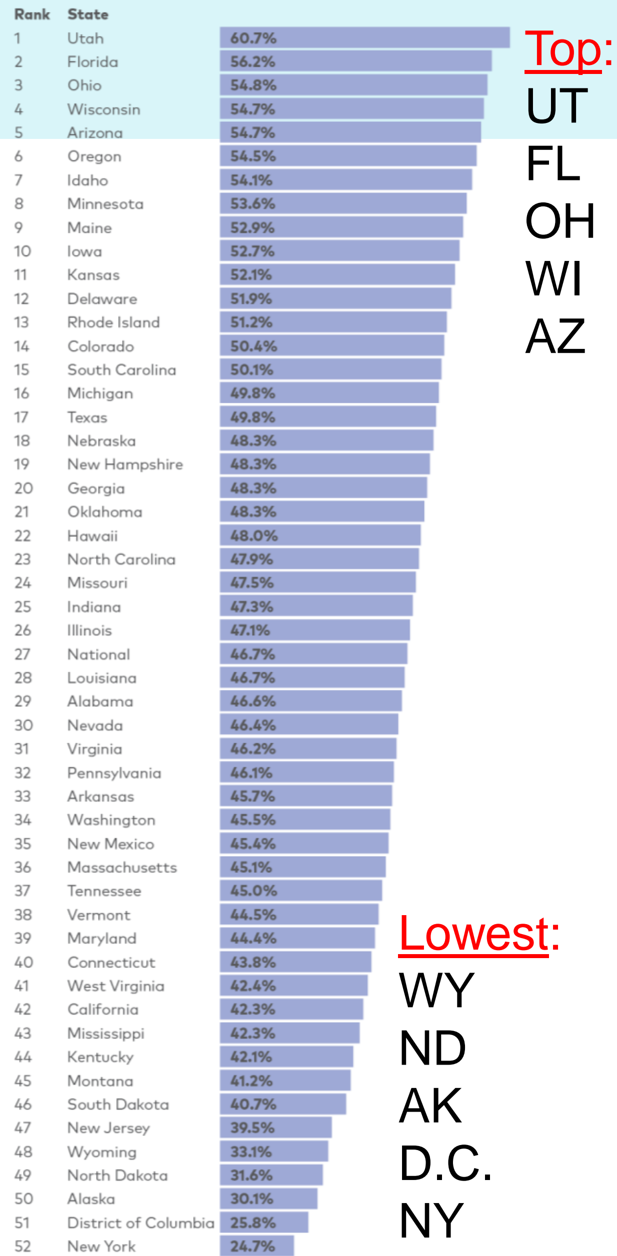


N Engl J Med. 2019 Dec 12;381(24):2369-2370.



- It is clear that fewer patients are dying at home than want to do so
- Hospice can be one way of increasing the likelihood that someone will die in their home

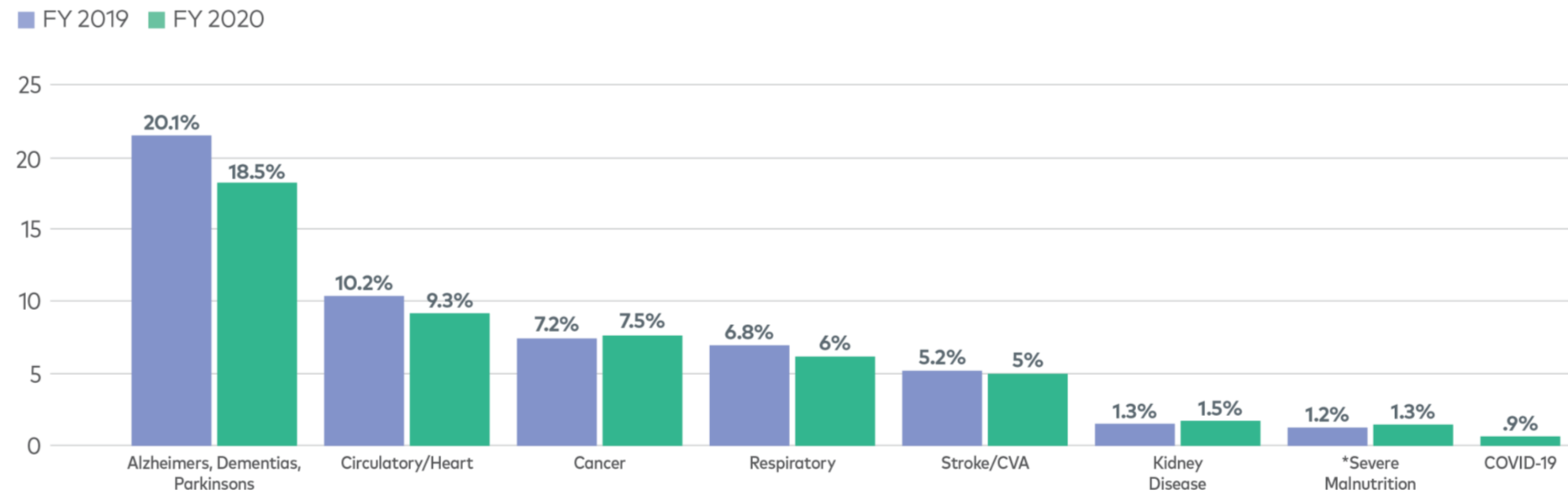
Figure 4: Hospice utilization by state (percentage)



Top:
UT
FL
OH
WI
AZ

Lowest:
WY
ND
AK
D.C.
NY

Figure 11: Medicare Decedents Using Hospice by Top 20 Principal Diagnoses (percentage)



Note: *Only the top 20 diagnoses were included in these groupings. Additional diagnosis that could fall under these groupings are outside of the top 20 diagnoses.*
Source: *Hospice Analytics*

2022 Edition: Hospice Facts and Figures. Alexandria, VA: National Hospice and Palliative Care Organization

Hospice: *When*

Parkinson's Foundation

Demonstrates evidence of advanced PDRD as manifested by either A, B, or C:	A. Critical **nutrition** impairment in prior year - inability to maintain sufficient fluid/caloric intake and dehydration, or - BMI<18, or - 10% weight loss over 6 months and refusal of artificial feeding methods); OR
	B. **Life-threatening complications** in prior year - recurrent aspiration pneumonia, sepsis, pyelonephritis - falls with fractures, - recurrent fever, - stage 3 or 4 pressure ulcers; OR
	C. Motor symptoms ~ poorly responsive to **DA meds** or which cannot be treated with DA medications d/t unacceptable SEs and result in significant impairments in ability to perform self-care
Rapid or accelerating motor dysfunction or **non-motor disease progression:**	**Motor**: including gait and balance **Non-motor**: severe dementia, dysphagia, bladder dysfunction, stridor (in MSA) and disability (restricted to bed or chair-bound status, unintelligible speech, need for pureed diet and/or major assistance needed for ADLs)
+**Advanced dementia** and meets **hospice referral criteria** based on:	Medicare's dementia criteria, Advanced Dementia Prognostic Tool criteria, or Minimum Data Set-Changes in Health, End-stage disease and Symptoms and Signs Score criteria

J Neurol Neurosurg Psychiatry. 2021 Mar 31;92(6):629–36

Hospice: *When*

Parkinson's Foundation

Modified surprise question:

"Would I be surprised if this patient died in the next 6 months?"

Clin J Am Soc Nephrol. 2008 Sep;3(5):1379-84

Hospice: *When*

Parkinson's Foundation

Getting hospice care *too late* causes problems such as:

- Team doesn't get a chance to move from greeting/info gathering to the supporting/problem solving phase of care
- Can feel like constant crisis mode
- There may not be enough time to get control of discomfort

Barriers to timely hospice care:

- Challenges of prognostication (or "not there yet")
- Lack of some services (PT, OT) which can be helpful
- Clinician discomfort in discussing, family/pt discomfort ("giving up")
- Variable medication coverage

Hospice: *Why* remain involved

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A neurologist can choose which role they would like to serve in the patient's care

- Primary Attending
  - Patient's main attending, gets called by nurse (or others) for all orders, symptoms, questions
  - Could be hospice medical director or patient's neurology provider
- Consulting Physician
  - Another physician (e.g., neurologist) involved in patient's care but not contacted for orders, symptoms
  - May get consulted for specific questions by the hospice team
- Referring Physician
  - Refers patient to hospice and is contacted by hospice when patient dies

Hospice: *Why* remain involved

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In either the primary or consulting role:

- Neurology clinician's input is highly valued for medication adjustments, **specialty-level expertise**, and procedures
- Neurology clinician can often continue to see patient in clinic to perform procedures and **adjust medications related to comfort and quality of life**
- Reminds hospice teams to **avoid contraindicated medications**
- Maintains the trusted, often long-standing relationship

Tips to consider: hospice collaboration

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- Invite local hospice groups to:
  - PDRD-specific symposia
  - Case presentations (esp when pt had been followed by hospice team)
  - Section/division meetings to provide presentations on their services
- Offer your residents/fellows to provide hospice in-service on PDRD-specific topics
- Designate a point-person in clinic who gets to know the local hospices by name

Palliative Care Town Hall

Muhammad Mahdi Nashatizadeh, M.D.
Director, Inpatient Movement Disorders
Clinical Associate Professor, Department of Neurology
University of Kansas School of Medicine

June 7, 2023

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Disclosures

Parkinson's Foundation

- I have been on the Board of Advisors for the Parkinson's Foundation Heartland since January 2021.
- There are no financial conflicts of interest.

Parkinson's Foundation

- **History of Palliative Care**
  - celebrating 20 years at KUMC in 2024
  - Kansas City, Wichita and Salina campuses
  - metropolitan, community and rural-based resources
  - secondary exposure in medical school during inpatient clerkships / rotations
  - clinical opportunities for residents specializing in internal medicine, neurology, and family medicine

Palliative Care Partnership at the Krupp Smith Family Foundation
Kansas University Medical Center (KUMC)
Parkinson's Foundation Center of Excellence (COE)

Parkinson's Foundation

- **Interaction**
  - longstanding relationship via the Alfred E. Landon Center on Aging
  - extensive neurohospitalist interaction weekly with palliative care attendings, nurse practitioners and social workers
  - historically outpatient palliative care was limited to cancer and heart failure
  - movement disorders fellows also have the opportunity to spend some time with palliative care faculty
  - Team Training October 2022 hosted in Overland Park, KS (Kansas City suburb)
  - also extended to our Amyotrophic Lateral Sclerosis (ALS) Clinic

Potential Tips for Success

1. Start with key stakeholders.
2. Expand to include more team members.
3. Engage in crucial conversations.
4. Maintain clear communication.
5. Continue to build bridges.

- **Education**
  - Dr. Shauna Gibbons will be a key presenter at our 15th Annual KU Parkinson's Disease Symposium on Saturday, August 12th, 2023.
  - All of our movement disorders fellows complete the entire Parkinson's Foundation Palliative Care in Parkinson's Disease course as they are team members in our Center of Excellence.
  - I am currently in the process of developing two Parkinson's disease-centered didactics for all incoming palliative care fellows.

Overview

Presentation

Lecture

Didactics

Symposium

Curriculum

Parkinson's Foundation

- **Research Opportunities**
  - observational data from the overall experience of involving outpatient palliative care in our Center of Excellence
  - potential collaborative research projects between palliative care and movement disorders fellows and faculty
  - potential posters at the American Academy of Neurology (AAN), Movement Disorders Society (MDS), International Neuropalliative Care Society (INPCS)
  - potential publications in the neurology or palliative care literature

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- **Recruitment**
  - neurologists who are fellowship trained in palliative care or movement disorders are uncommon but slowly increasing in number
  - there is significant opportunity to develop new programs:
    - solid movement disorders program
    - solid palliative care program
    - solid physician leadership to recognize growth potential
    - solid institutional support

Thank you!

Muhammad Mahdi Nashatizadeh, M.D.

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Palliative Care Town Hall:

Collaboration and Partnership with Hospice and Palliative Care

Nicole Cool, BSN, RN
COE Nurse Coordinator
Movement Disorders Program
Medical University of South Carolina

June 7, 2023

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Outline

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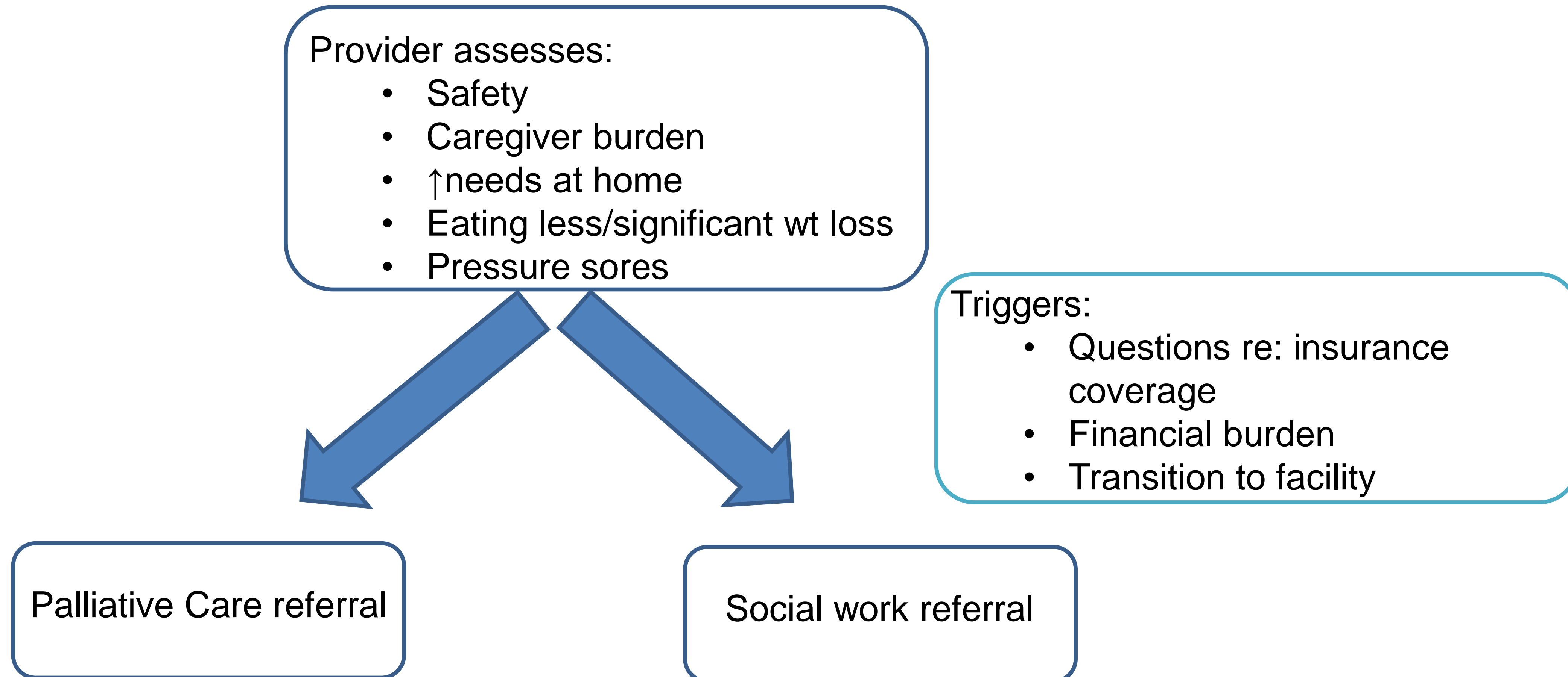
- How our team introduces palliative and/or hospice care to patients and families
  - The role of a COE RN coordinator
- When to refer to palliative care vs hospice care?
- Palliative care and hospice referral processes at MUSC
- Outpatient vs in-home palliative care
- Case study

How team discusses palliative care with patients/families

Parkinson's Foundation



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Nurse Coordinator

Contact patient and caregiver and assess needs for:

- Home health services including nursing and aide
- Palliative outpatient vs in-home
- Palliative vs hospice care

Home health

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- If caregiver is having difficulty with bathing, needs help with medication management, skin checks, and/or PT/OT/SLP needs.

Palliative Care: Outpatient vs In-Home

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- Would suggest outpatient palliative care for future planning, improving QOL, and additional support if patient's mobility allows for outpatient visits.
- Would recommend palliative in-home if mobility is limited, and if possible need for DMEs (such as hospital bed, Hoyer lift, etc).
    - Can have in-home evaluation for potential hospice care if necessary.

Palliative vs Hospice care: Tips

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- Educate early on the services available for patients under palliative care vs hospice care.
  - In general, we prefer palliative for our patients as long as possible so they are still able to get home health therapies and keep moving.
- Use a company that can provide both palliative and hospice so they can transition easily.
  - It is important to get to know your local hospice companies and the services they are willing to provide.
- We still see our patients even though they are on hospice but will not manage their hospice care.
- Be an advocate for your patients and caregivers!

Case Study

Parkinson's Foundation

79M w/ PD x17 yrs, in assisted living under hospice care.

- 2 daughters rotating as caregivers
- In clinic, more confused than normal. Daughters reporting decreased PO intake.
- UTI and started on Abx but confusion remained.
- 1* neurologist requested labs, ordered fluids for dehydration.
- Facility would not give fluids per medical director d/t hospice status.
- Daughters transferred to new hospice company. Admitted to new hospice company on a Saturday and received IV fluids.
- Months later patient walked into clinic for office visit with NO confusion.
- 2 months after admission to hospice B, transferred to *palliative services* and is receiving therapies to date.

Takeaways

Parkinson's Foundation

- Introduce the “palliative” approach early
  - Normalizes discussions around advance care planning and hospice
- Strengthen relationships with local palliative care and hospice companies
- Listen to the needs of the patient and family
- Be an advocate

Parkinson's Foundation

QUESTIONS & ANSWERS

Moderated by:

Christina L. Vaughan, MD, MHS
Associate Professor
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Section of Neuro-Palliative Care
University of Colorado, Anschutz Medical Campus

Thank you for participating!

Please keep an eye out for future Palliative Care programs from the Parkinson's Foundation!

ALSO: Upcoming virtual program for the PD community:

Preparing for Your Future: Advance Care Planning, Goal of Care

Wednesday, July 12, 1pm ET

Speakers: **Tom Carroll, MD, PhD**, Associate Professor of Medicine, Divisions of General Medicine & Palliative Care, University of Rochester and **Andrew Huang, MD**, Hospital and Palliative Medicine Fellow, Division of Hospice and Palliative Medicine, University of Rochester Medical Center

Register at: www.parkinson.org/pdhealth