Palliative Care & Advance Care Planning for Parkinson’s

Steve Lai MD
Margaret Stephens
Palliative Care & Support Services
Palo Alto Medical Foundation
By the end of this talk, you will be able to...

- Ask yourself 3 important questions to help plan for future medical decisions
- Understand advance care planning specifically for Parkinson’s, what to expect at end of life
- Understand palliative care vs hospice, PAMF palliative care service
- Complete Advance healthcare directive & POLST form
PD does contribute to mortality (71%) and there are certain signs and symptoms that predict terminal phase of disease.

Common causes of death - sepsis, respiratory failure, wasting syndrome, choking.

One study looking at predictors of mortality in PD at 6-12 months include accelerated weight loss, significant reduction in dopaminergic meds due to neuropsychological side effects.

Weight loss, dysphagia of liquids & aspiration, recurrent infection, accelerating loss of function & mobility - hospice would be appropriate.
Parkinson’s and End of Life Care

- Significant underutilization of palliative care & hospice
- <5% of Parkinson’s patients use hospice
- Majority die in hospital, one study showed that 97% of Parkinson’s patients who died in the hospital lacked a documented goals of care conversation or advance directive
- Patients who complete advance care planning are much more likely to die at home
What is Advance Care Planning?

- Making decisions for the health care you would want if you become unable to speak for yourself

- These are your decisions to make, regardless of what you choose for your care

- The decisions are based on your personal values, preferences, and discussions with your loved ones
Choose a DPOA/Healthcare Proxy

A good decision maker...

- Knows they are your DPOA
- Is available and easy to reach
- Knows your values
- Can make decisions *on your behalf*
Important Questions

- What brings me joy? What makes life worth living?

- What would be important to me if I became seriously ill or near the end of my life?

- What quality of life would be unacceptable for me?
Goals, Values, Priorities

Health Status / Prognosis

- Comfort Care
- Nursing Home
- ICU
- Chemotherapy
- Dialysis
- Life-Prolonging Treatment
- Hospice
- Artificial Nutrition
- CPR
- Ventilator
- Nursing Home
- ICU
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- CPR
- Ventilator
What is Palliative Care?

Specialty in medicine for **people living with a serious illness** with the goal to **improve quality of life for both the patient and the family**

Based on the **needs of a patient** than the prognosis of a patient, and appropriate at **any age, at any point** in a serious illness, and can be delivered **with curative treatment**
How Do I Get Palliative Care at PAMF?

Ask your doctor to place a referral to Palliative Care and Support Services (PCSS)

Locations in San Mateo, Palo Alto, Sunnyvale, Fremont, Dublin, and Santa Cruz

- Home visits
- Video visits
Difference between Palliative Care and Hospice

Palliative Care
- Specialty service that works in collaboration with other medical providers including Primary Care.
- Works with primary treatment being provided.
- Focus is on Symptom management/pain and stressors of serious illness as an adjunct to curative care modalities.
- Not necessarily time limited. Appropriate at any stage of illness.
- Focus on providing medical guidance and support based on the quality of life measures defined by the individual’s goals and values.

Hospice
- Focuses on Comfort and symptom management during the terminal phase as defined by Medicare as having a life expectancy of 6 mo or less.
- Hospice admission requires a change in condition. A decline related to a terminal prognosis. For example, decline or sudden change in functional status/mobility, cognition, weight loss etc.
- Hospice should be considered when the burden of treatment outweighs the benefit coupled with prognosis.
What is POLST?

- A physician order recognized throughout the medical system.
- Portable document that transfers with the patient.
- Brightly colored, standardized form for entire state of CA.
Why POLST?

1. Patient wishes often are not known.
   - The Advance Health Care Directive (AHCD) may not be accessible.
   - Wishes may not be clearly defined in AHCD.

2. Allows health care professionals to know and honor wishes for end-of-life care.
What is POLST?

- Allows individuals to choose medical treatments they **want** to receive, and identify those they **do not want**.

- Provides direction for health care providers during serious illness.
Who Needs POLST?

- Chronic, progressive illness
- Serious health condition
- Medically frail
- Tool for determination
  - Would you be surprised if this patient died within the next year.”
Where Does POLST Fit In?

Advance Care Planning Continuum

Age 18

Complete an Advance Directive

Update Advance Directive Periodically

Diagnosed with Serious or Chronic, Progressive Illness \textit{(at any age)}

Complete a POLST Form

End-of-Life Wishes Honored
AHCD vs. POLST

AHCD
- Legal Document
- The Individual completes it.
- All adults whom are able to make their own decisions should have one.
- Appoints a surrogate.
- Communicates General Wishes.

POLST
- Medical Order
- Healthcare Professional completes it.
- People who are considered high risk for life-threatening clinical events because they have a serious life-limiting medical condition.
- Does not appoint a surrogate.
- Communicates specific medical orders.
Questions