# 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

## Parkinson's & Mortality

- 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</p>
- 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?

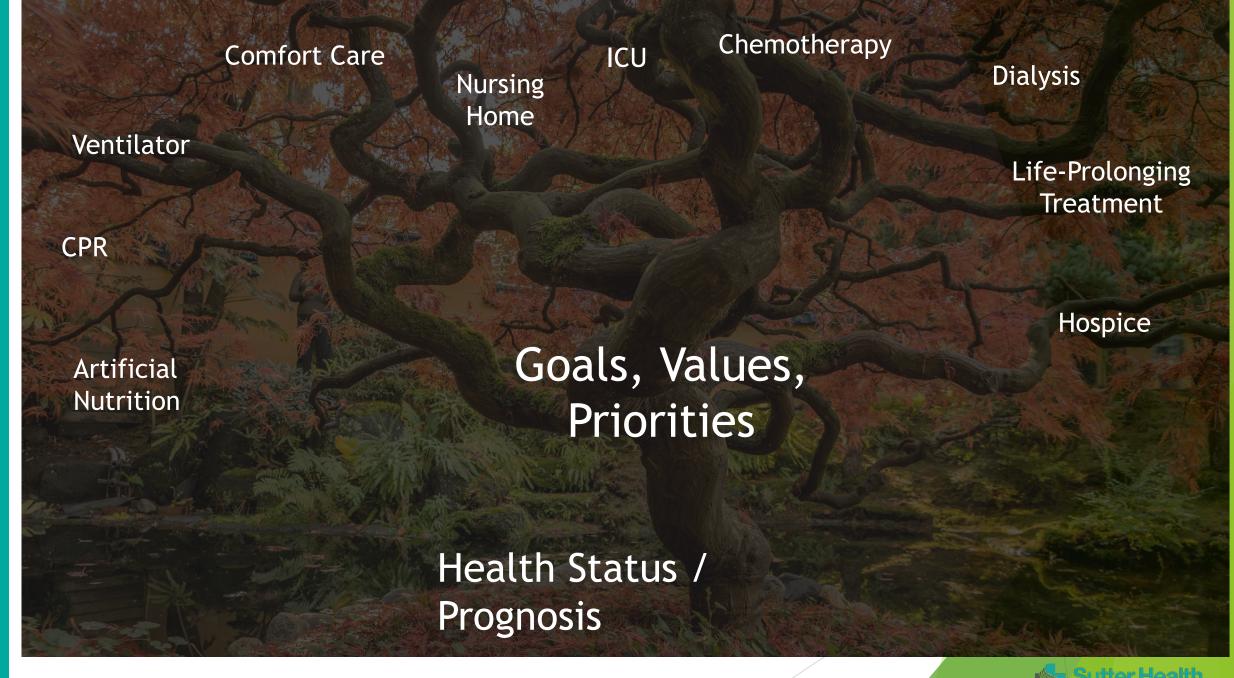
What would be important to me if I became seriously ill or near the end of my life?

What quality of life would be unacceptable for me?











### 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?

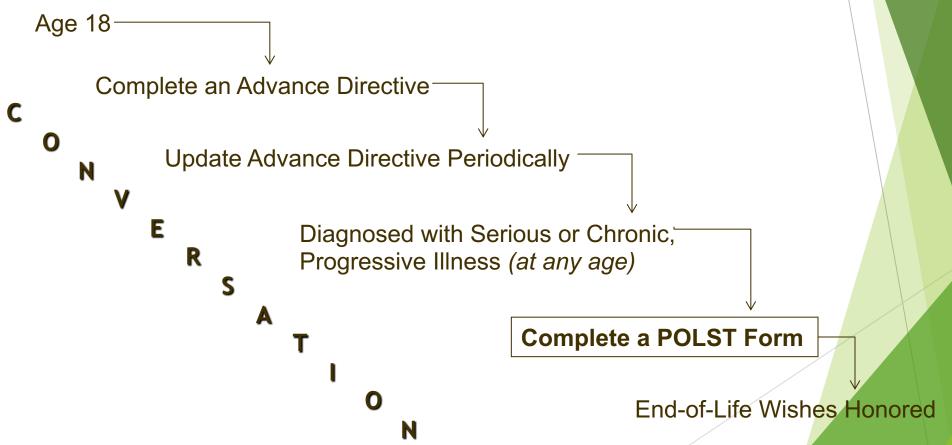
- Allows individuals to choose medical treatments they <u>want</u> to receive, and identify those they <u>do not want</u>.
- Provides direction for health care providers during serious illness.

#### 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



## 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