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Palliative  
Care

# Living Your Best Life with Multiple Systems Atrophy

*A presentation developed and supported by:*  
Stanford Movement Disorders  
Stanford Palliative Medicine



[www.med.stanford.edu/palliative-care](http://www.med.stanford.edu/palliative-care)



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# Roadmap

- What is palliative care?
- How is palliative care different from other parts of medicine?
- When and how can someone benefit from palliative care?
- How does palliative care help people live their best life?
- The difference between palliative care and hospice



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What is palliative care?



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# What is palliative care?

- What comes to mind when you hear the term palliative care?

# How is palliative care different?

- Palliative care centers upon *the person* beyond the disease.



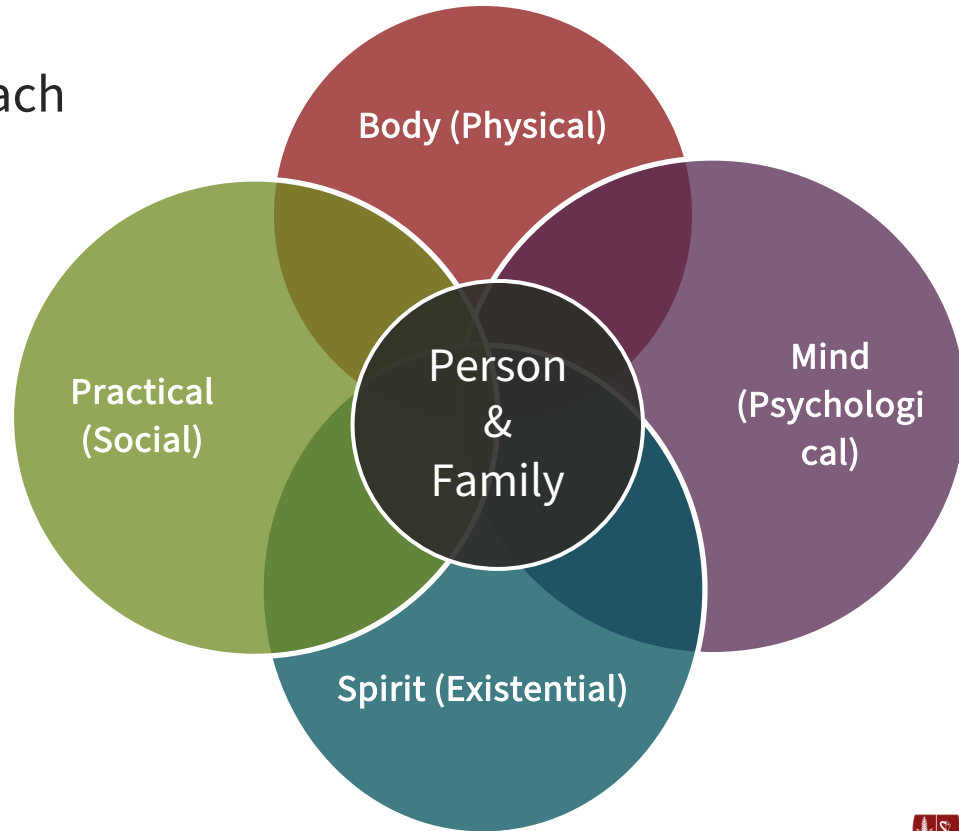
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# How is palliative care different?

- A holistic approach



*Derived from World Health Organization definition of palliative care, 1998*



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# How is palliative care different?



## Doctor & Nurse

- Prescribes medication
- Helps with medical decisions
- Coordinates with other doctors



## Social Worker

- Emotional Support
- Caregiver support
- Medical equipment
- Financial concerns



## Chaplain

- Spiritual support
- Existential distress
- Prayers and blessings





# Defining palliative care

- **Definition:**
  - Palliative care is specialized health care for **people living with a serious illness.**
  - This type of care is focused on **providing relief from the symptoms and stress of the illness.**
  - The goal is to **improve quality of life** for both the **patient and the family.**

# Defining palliative care

- Provided by a specially-trained **team**, palliative care specialists work together with a patient's other doctors to **provide an essential layer of support**.
- Palliative care is based on the needs of the patient, not on the prognosis. It is appropriate **at any age and at any point in a serious illness** and **can be delivered alongside curative treatment**.





# Living with a serious illness

## Common Diagnoses

- Cancer
- Heart failure
- Multiple systems atrophy
- Atypical parkinsonian conditions
- Parkinson's Disease
- ALS



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# Relief from MSA symptoms and stress



- Pain
- Difficulty breathing
- Muscle spasms
- Increased saliva
- Irritability
- Anxiety
- Depression
- Coping
- Fatigue
- Low appetite



# How do we relieve symptoms?



# Help with medical decisions

- Advance Health Care Planning
- Completing **Advance Directives** and POLST forms
- Weighing **treatment options**





# Any age, any stage, with any treatment

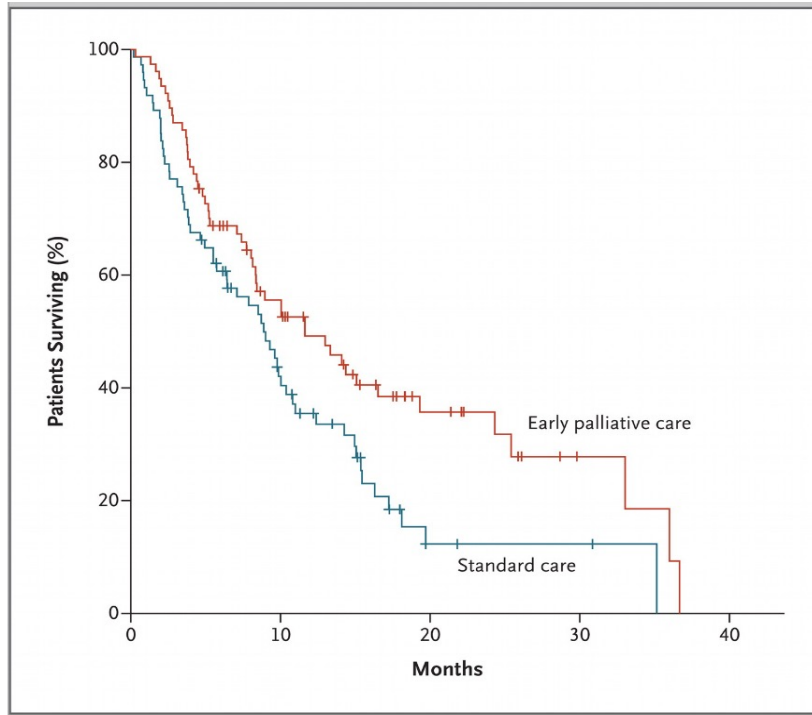
- Palliative Care is appropriate at **any age** and can be provided **alongside any type of treatment**.
- Examples of patients I see in clinic:
  - **New diagnosis**
  - Pursuing **treatment**
  - Pursuing **clinical trials**
  - Living with their illness and **not receiving treatment targeting their underlying illness**



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# If it were a pill...



- Median Estimates of Survival:
  - 11.6 months early PC group
  - 8.9 months in standard group

# Palliative care has many benefits

- Improved
  - Quality of life
  - Symptom control (i.e. pain, shortness of breath)
  - Spiritual wellbeing
  - Psychological symptoms
  - Satisfaction with care
- Fewer hospitalizations
- Fewer hospital days
- Less burden on caregivers



# When to ask for palliative care



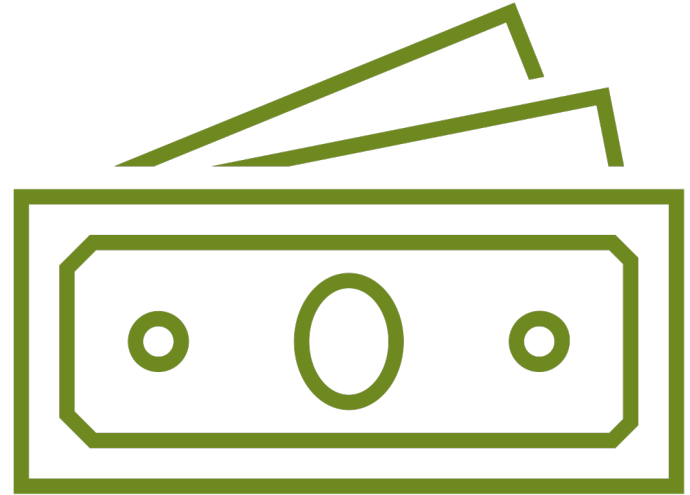
- Serious illness
- Difficult symptoms
- Difficult decisions
- Difficulty coping
  
- Multiple domains of life affected
  - Body
  - Mind
  - Spirit





# Who pays for palliative care?

- **Covered** by insurance like any other medical specialty clinic
- SB 1004 in California has helped promote access to palliative care for patients **covered by public health insurance**



# How do I access palliative care?



- Referral from:
  - Primary Care Provider
  - Primary Specialist (e.g. cardiologist, oncologist)
  - Inpatient medical team or ED



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# Palliative Care

Hospice



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# What is hospice?

1. A philosophy of care
2. An insurance benefit
3. A set of services



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# Hospice as a philosophy of care



- Comfort-focused care
- Delivered where patients want to be



# Hospice as an insurance benefit

- Covered by nearly all insurance plans (including Medicare and Medicaid)
- Insurance provides eligibility guidelines:
  - 2 doctors assess that more likely than not that prognosis is 6 month or less
- Hospice primarily covers treatments that provide comfort-focused care
- Discussion about specific treatments is possible



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# Hospice as a set of services

- Interdisciplinary Team
  - Doctor
  - Nurse-Case Manager
  - Social Worker
  - Chaplain
  - Volunteer
  - Home health aide
- Home-Based Care (if desired)
- 24hr Nurse Call Line
- Ability to send “on demand” nurse to home
- Ability to transfer to nursing home if desired
  - Does not cover cost of room & board
- Prescribe and provide medications for symptom relief
- Prescribe and provide all medical equipment
  - Hospital bed
  - Bedside commode
  - Wheelchair
- Does not provide 24hr care



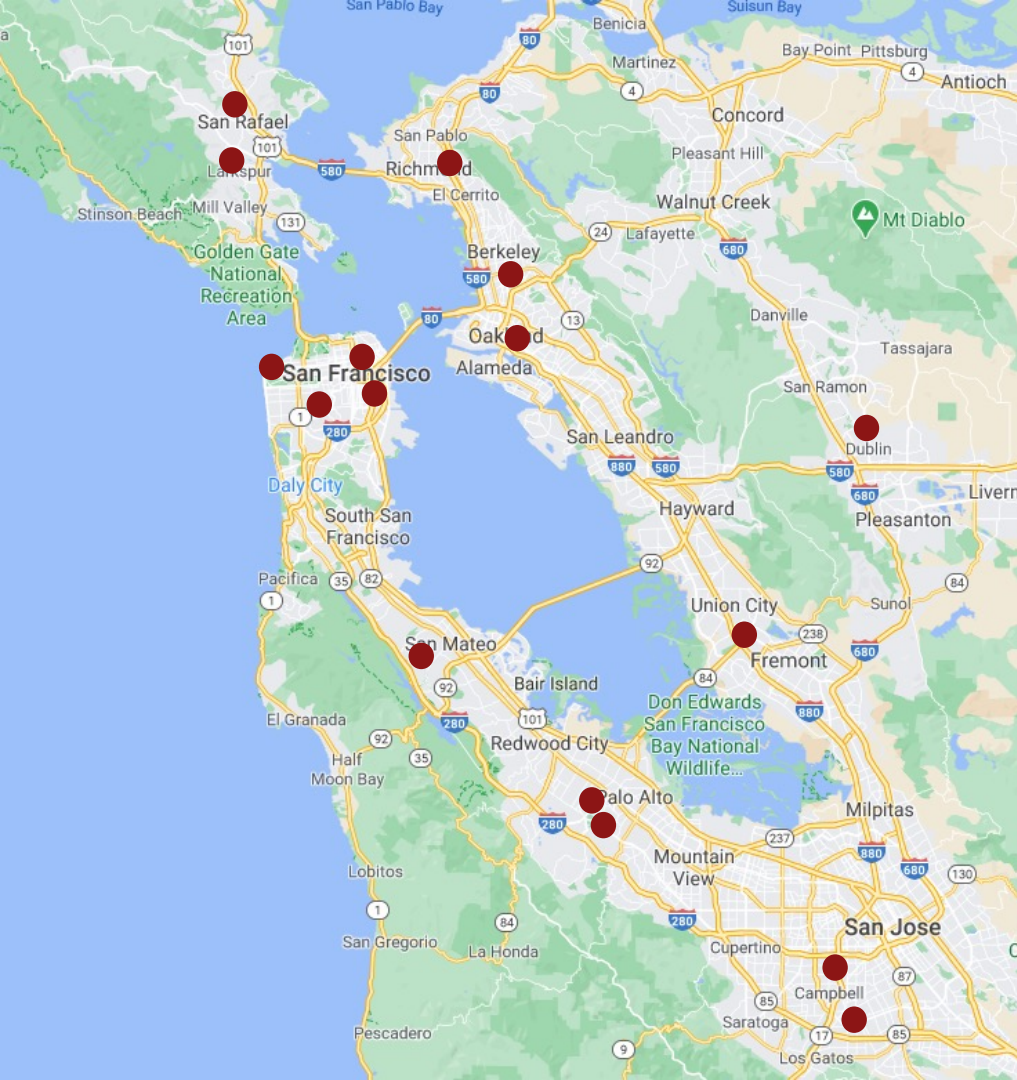


## Resources



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# Palliative care programs

- Kaiser Marin-Sonoma
- Marin General Hospital
- Kaiser East Bay
- San Francisco Veterans Administration
- Sutter San Francisco/California Pacific Medical Center
- Kaiser San Francisco
- UCSF
- Zuckerberg San Francisco General Hospital
- Sutter/Palo Alto Medical Foundation (PAMG)
- Stanford
- Santa Clara Valley Medical Center
  
- **GetPalliativeCare.org**



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# Take home message

- If you are facing difficult road, palliative care is here to partner with you to improve quality of life and to navigate difficult decisions.



# The Stanford Neuropalliative Clinic

- Interdisciplinary specialist palliative care for people living with serious neurological disease
- Virtual and in-person visits are available
- Available to patients in the Stanford Healthcare System
- Referrals can be placed by any provider (primary care provider, neurologist)
- Referral to Palliative Medicine at 213 Quarry Rd (Stanford Neuroscience Health Center)



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# Thank you!



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