Caring for the Whole Person in Parkinson’s Disease

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www.med.stanford.edu/palliative-care
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
What is Palliative Care?
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.
How is Palliative Care Different?

- A Holistic Approach

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

*Center to Advance Palliative Care (CAPC), 2019*
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.

Center to Advance Palliative Care (CAPC), 2019
Living With a Serious Illness

Common Diagnoses

- Cancer
- Heart failure
- Parkinson’s Disease
- Dementia
- ALS
Relief From PD Symptoms and Stress

- Pain
- Constipation
- Muscle spasms
- Increased saliva
- Agitation
- Anxiety
- Depression
- Coping
- Fatigue
- Low appetite
- Caregiving
How Do We Relieve Symptoms?

Symptom

Medications

Psychological

Integrative

Spiritual
Help with Medical Decisions

- Advance Health Care Planning
- Completing Advance Directives and POLST forms
- Weighing treatment options
Any Age, Any Stage and Can Be 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
If it were a pill...

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

Temel (2010) *NEJM*
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
A Patient quality of life QOL-AD

B Patient quality of life ZBI

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
Palliative Care

Hospice
What is hospice?

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

- Prescribe and provide medications for symptom relief
- Prescribe and provide all medical equipment
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 (PAMF)
- Stanford
- Santa Clara Valley Medical Center

GetPalliativeCare.org
Resources for Palliative Care

- For more information about Palliative Care:
  - Stanford Website:
    - [https://med.stanford.edu/palliative-care](https://med.stanford.edu/palliative-care)
  - PalliativeDoctors.org:
    - [https://palliativedoctors.org/](https://palliativedoctors.org/)
  - National Hospice and Palliative Care Organization (NHPCO):
    - [https://www.caringinfo.org/](https://www.caringinfo.org/)

- For finding a palliative care program near you:
  - [https://getpalliativecare.org/](https://getpalliativecare.org/)
Palliative Care is here to partner with you

- ...your family, and your neurologist in carrying the load.
The Stanford Neuropalliative Clinic

- Interdisciplinary specialist palliative care for people living with neurological disease
- Virtual and in-person visits are available
- Available to patients in the Stanford Healthcare System
- Referral to Palliative Medicine – specify “for neuropalliative care” and my name (“Jocelyn Jiao”)
- Referrals can be placed by any provider
Thank you!

www.med.stanford.edu/palliative-care

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