

# Supportive Care & Living Well with Parkinson's

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**DAVIS PHINNEY**  
Foundation For Parkinson's

*every victory counts.*

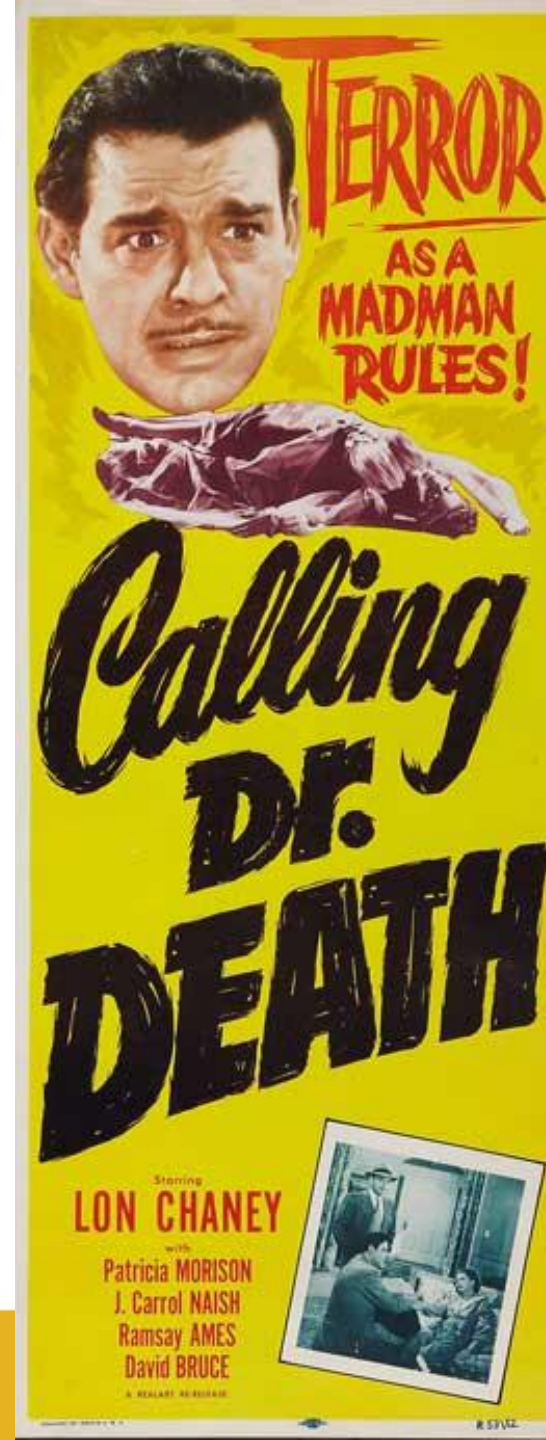
# Defining Terms

What is supportive care? Palliative Care? Hospice?



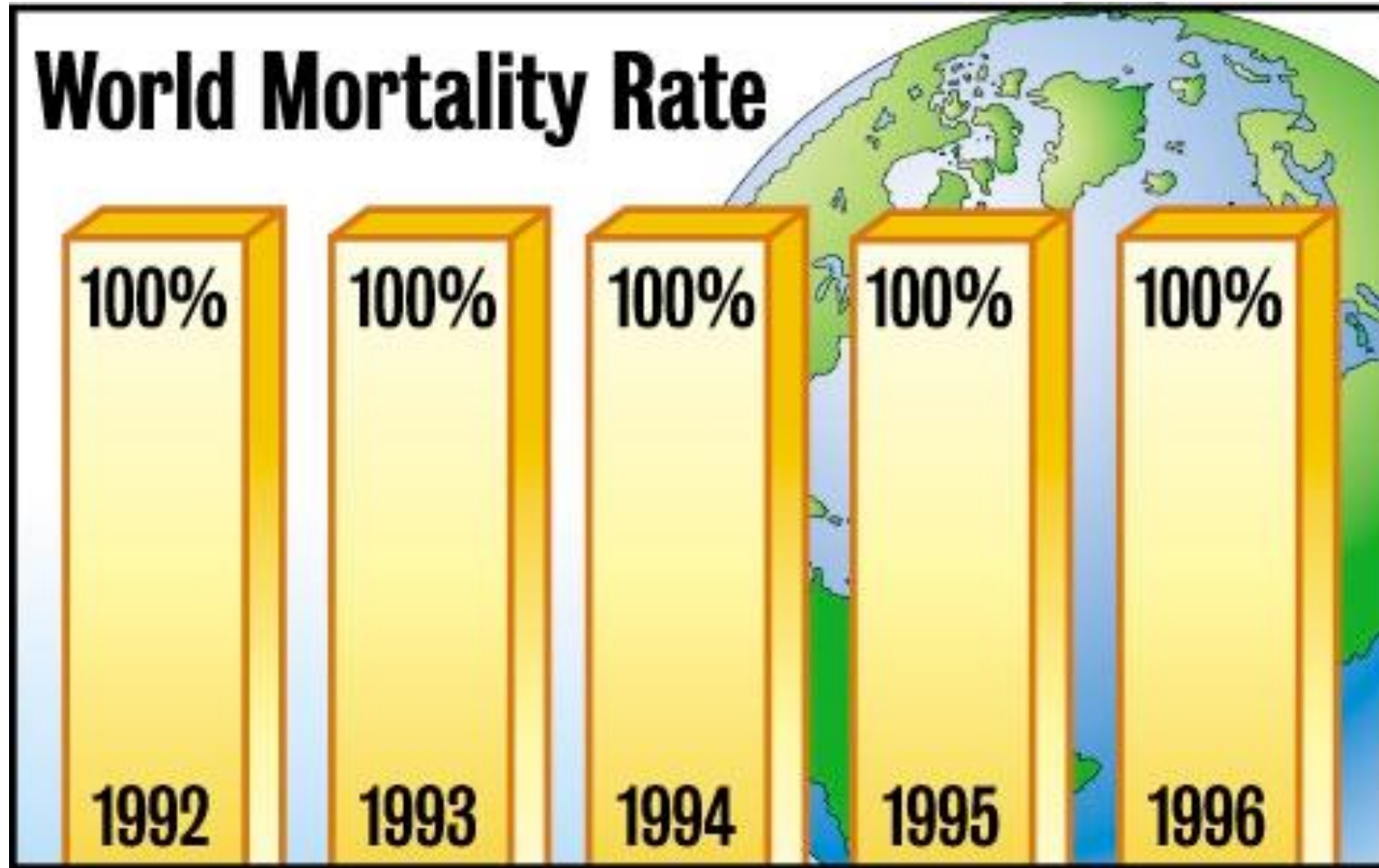
## Palliative Care is NOT

- Palliative care includes but is not the same as hospice
- Euthanasia or Death Squads
- Giving up on patients
- Only for the imminently dying
- Only for patients with cancer
- Only for palliative care specialists



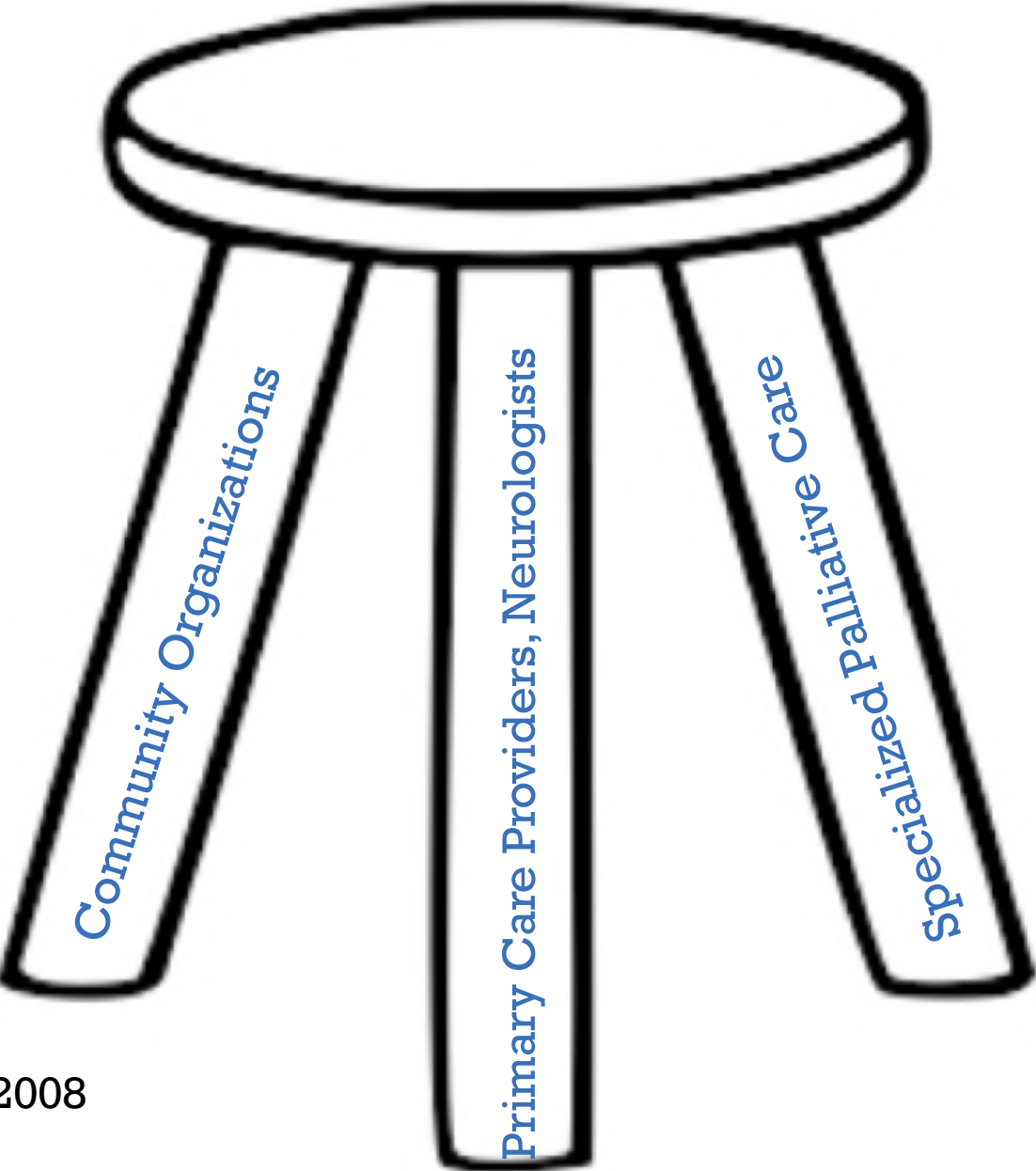
# **Palliative and Supportive Care Defined**

- Primary goal is to improve quality of life and relieve suffering for patients and their families
- Includes control of pain and other hard to control physical symptoms
- Also addresses psychological, social, and spiritual issues
- Palliative care affirms and supports life while addressing death and decline as a normal and expected process





# Palliative Care as a System: The 3-Legged Stool



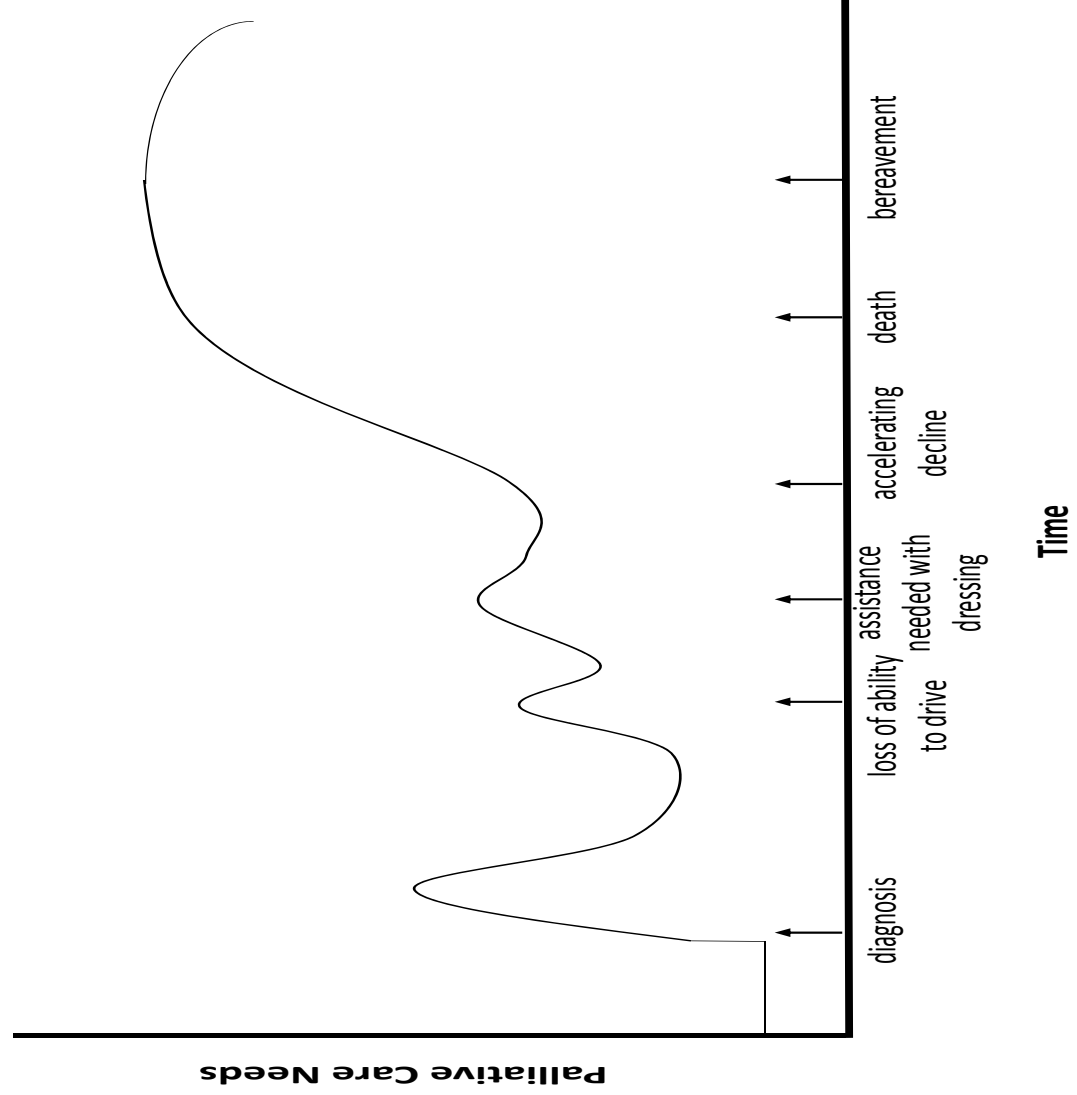
Developed by Kirk Hall, living with Parkinson's since 2008

# Hospice

- Palliative care for persons nearing the end of life (defined as 6 months by Medicare) – you can (and might) live longer
- 90% of hospice is at home and it is covered by Medicare, Medicaid and other insurances
- Goals of hospice are to keep people at home and comfortable
- Services provided by hospice include medical support, social work chaplain, medical equipment and other services

# When is the right time? Now is the right time.

Figure 1: Continuum of Palliative Care





# Finding Opportunities for Love, Joy, Meaning and Connection

What are goals of care?

What is Person vs. Patient vs. Disease-centered Care?

# Are you an illness, a patient or a person?

- In palliative care, we take care of people, not illnesses.
- How do you define yourself:
  - Values
  - Connections
  - Activities
  - Gifts and skills
- How do you want to be seen?
- What is essential and untouchable?
- Finding wholeness versus returning to normal

## **Goals of Care should inform Plans of Care**

- What do you enjoy?
- What are you looking forward to?
- Where do you find meaning?
- Where do you find joy?
- Who do you love?
- How do you find peace?
- What are you afraid of?
- What is the hardest part of having Parkinson's?



# Opportunities for Joy

- Meaning
- Connection
- Simple Pleasures
  - Food
  - Touch
  - Music
  - Nature

# Addressing Sources of Suffering

Palliative approach to symptom management

Working with challenges to emotional and spiritual wellbeing



# Symptom Management

- Pain, fatigue, depression, memory loss, apathy
- Can we find ways to reduce these symptoms?
- Can we reduce *the impact* of these symptoms by focusing on function?
- Can we find ways *to live* (not just survive) despite these symptoms by creating shared goals and dropping unrealistic expectations?
- Can we find ways *to cope* better with these symptoms?

# Difficult Emotions

- Grief, guilt, worries, hopelessness, loneliness
- We can NURSE these difficult emotions
- Naming
- Understanding
- Respecting
- Supporting
- Exploring

# Spiritual Challenges

- Spirituality refers to how you find meaning, connection, choice and stillness
- Parkinson's may challenge one's faith, hope, courage, identity, relationships and sense of self
- Spiritual practices can be a source of strength, courage, patience and resilience

## **Real vs. False Hope**

- Hope is critical to avoid demoralization
- False hope can cause one to make bad decisions and waste precious time and other resources
- Real hope helps one to focus on what's most important and on real choices in the here and now

# Planning and Preparing for the Future

Developing a Road Map for the Parkinson's journey

# Moving Beyond “Everyone is Different”

- Simply knowing that everyone with Parkinson's has a different journey is not very helpful
- Many people want a road map:
  - Where am I on the journey?
  - What do I need to watch out for?
  - What does the end of the road look like?



## **Road Signs**

- These depend on where you are on the map
- Early on one may be watching for signs that they should retire, consider DBS, start Parkinson's medication
- In the middle stages, signs may include problems with memory, balance or activities of daily living
- In advanced disease, patients and families may need guidance on whether to get outside help, go to a nursing home and when to start hospice

# Advance Care Planning

- This is an active conversation between patients, families and healthcare providers
- Includes:
  - Power of attorney
  - Advance directives
  - Anticipatory guidance
  - Goals of care

# Power of Attorney and Advance Directives

- Who do you want (or not want) to make decisions for you if you cannot do this for yourself?
- Do you want CPR?
- Do you want aggressive interventions?
- Do you want to avoid interventions not likely to improve your quality of life?
- Do you want to avoid hospitals?

# Summary and Action Items

## **Action Items**

- **Make a bucket list**
- **Get in touch with your spiritual self**
- **Write down opportunities for joy**
- **Talk to your family about your wishes now and in the future**
- **Complete a power of attorney and advance directives**