

Here When You Need It: Supportive Care

Benzi Kluger, MD, MS, FAAN
Professor of Neurology and Medicine
University of Rochester

Learning Objectives

- Define palliative care and distinguish the palliative care approach from specialist palliative care/hospice
- Identify situations and symptoms where palliative care may improve the lives of people living with PD and their families
- Employ palliative care strategies and services to improve self-care and the healthcare you receive from diagnosis onwards

Palliative Care

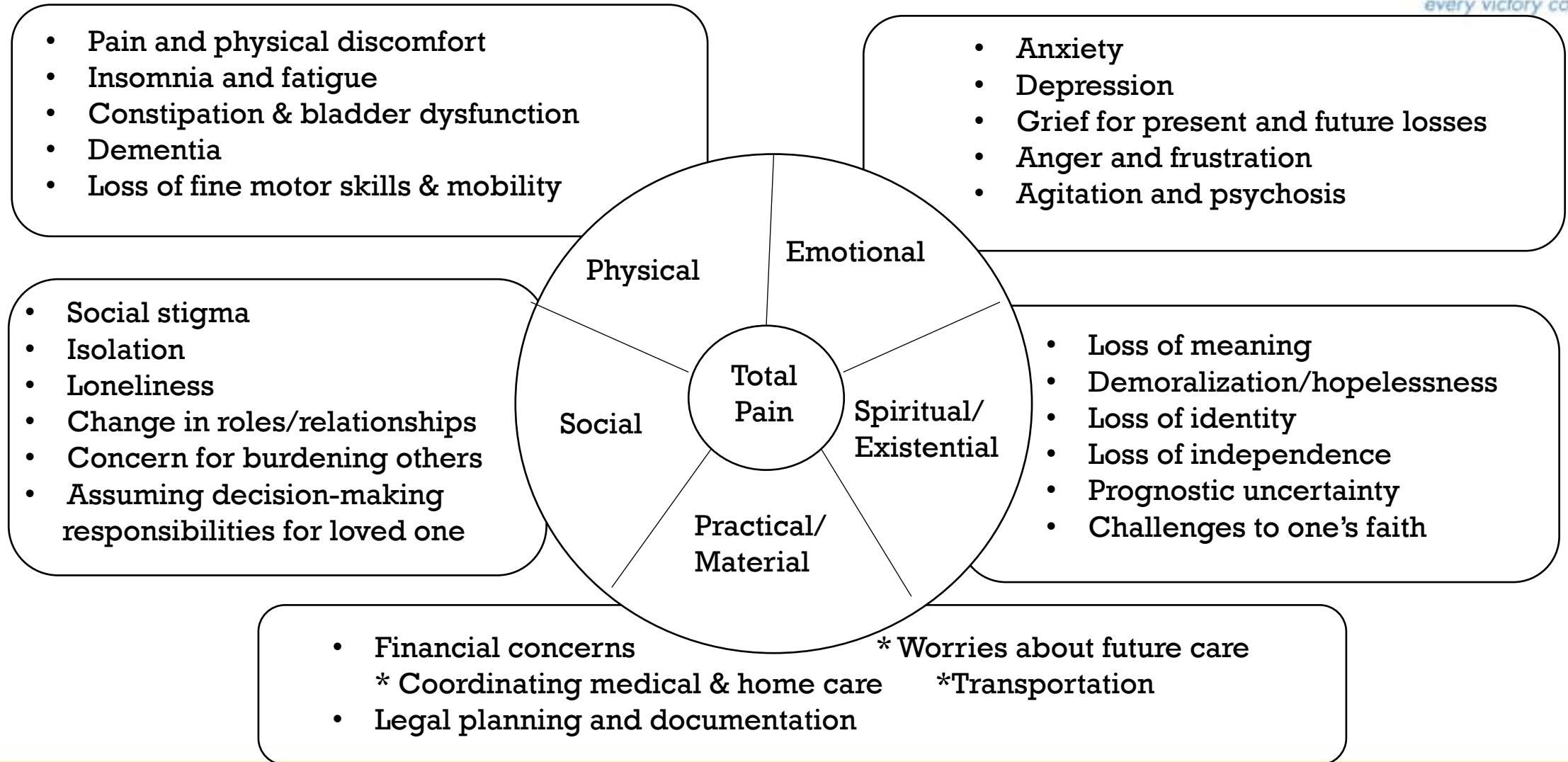
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**Living your life as well as you
can with an illness that sucks.**

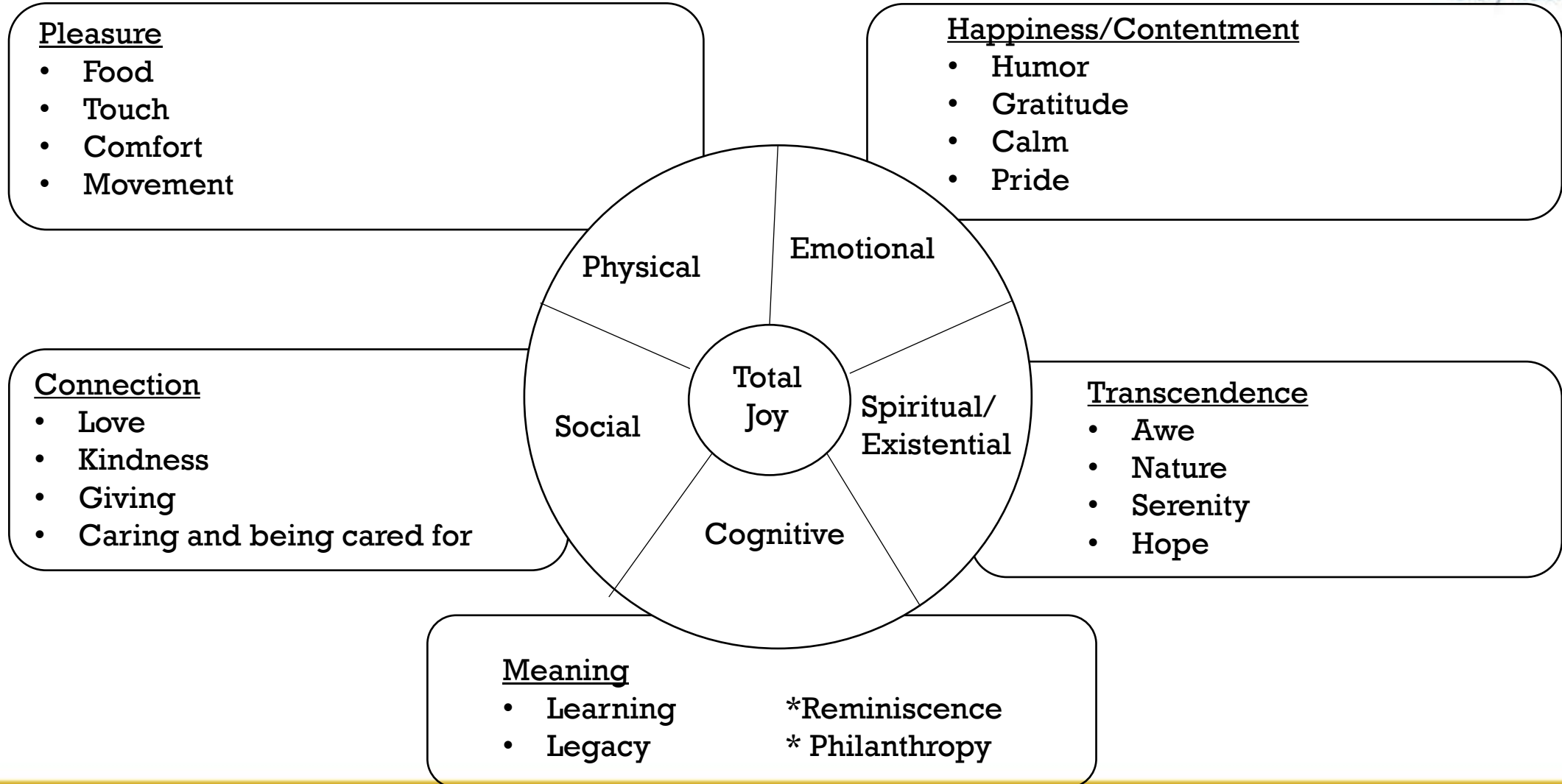
**Getting the diagnosis of
Parkinson's is like a
bomb being dropped in
your life.**



Parkinson's Causes Multidimensional Suffering for PWP & Family



The Need to Enjoy Life Does Not End with Parkinson's



The goal of palliative care is to improve the quality of life of patients and families by anticipating future sources of suffering, addressing current sources of suffering, and exploring opportunities for joy, hope, love & meaning.

People can die from complications of Parkinson's.



Most people with Parkinson's get palliative care too late (if at all).

You have the power to change this.

Raising Standards of Care for Parkinson's

VIEWPOINT

Palliative Care and Parkinson's Disease: Time to Move Beyond Cancer

Benzi M. Kluger, MD, MS,^{1*} Rachel Dolhun, MD,² Malenna Sumrall, PhD,³ Kirk Hall, MBA,³ and Michael S. Okun, MD^{4,5}

¹*Departments of Neurology and Medicine, University of Rochester Medical Center, Rochester, New York, USA*

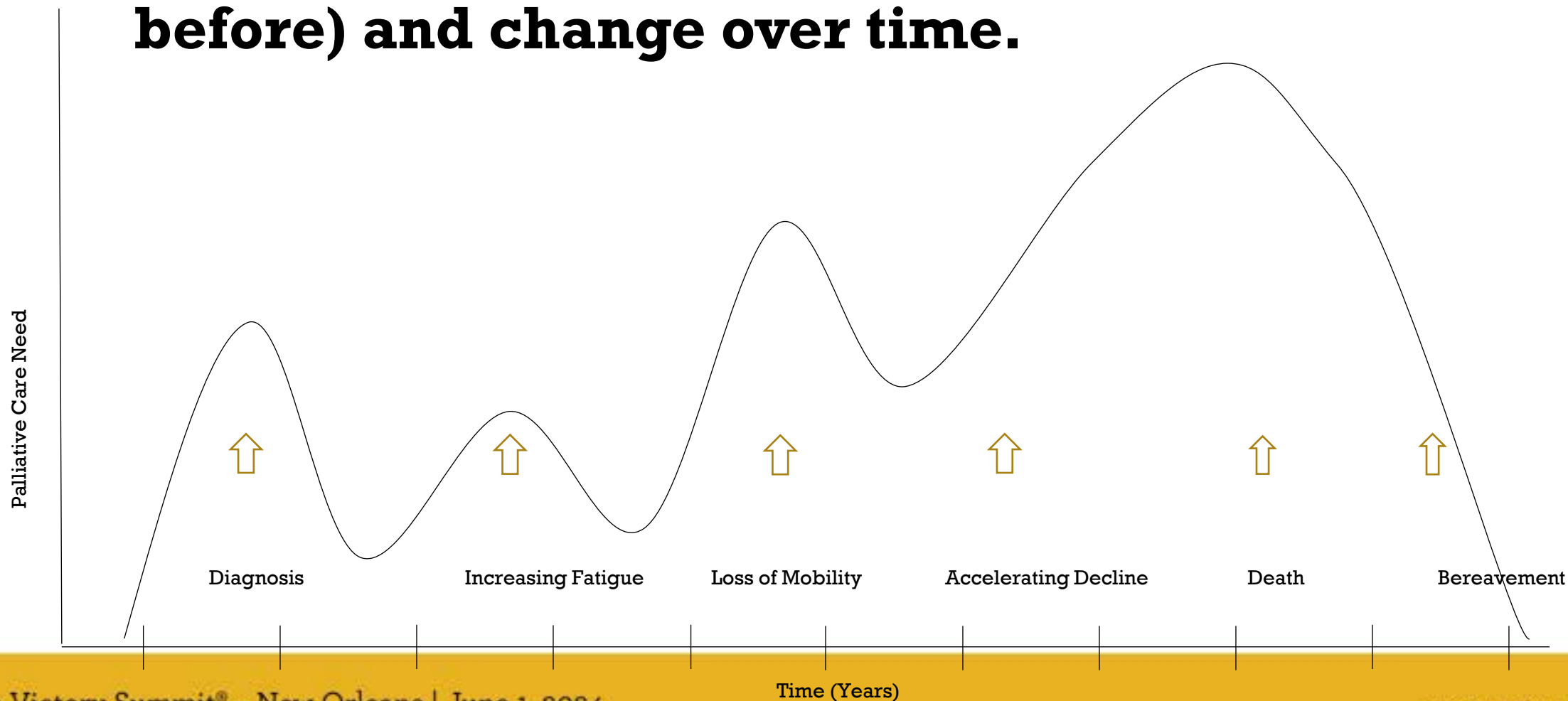
²*The Michael J. Fox Foundation, New York, New York, USA*

³*Parkinson Foundation Patient and Family Advisory Council, New York, New York, USA*

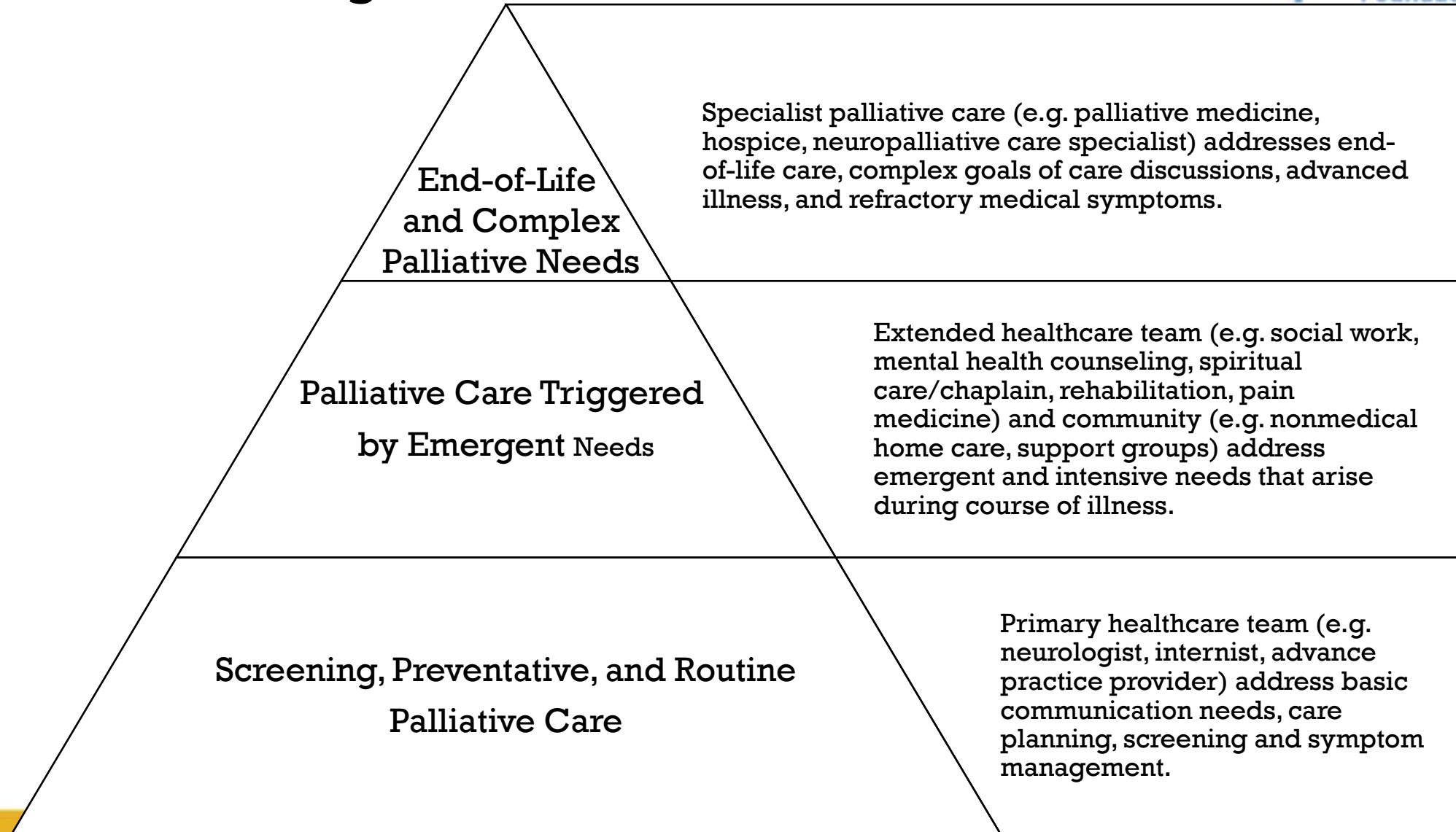
⁴*Department of Neurology, Norman Fixel Institute for Neurological Diseases, University of Florida, Gainesville, Florida, USA*

⁵*Parkinson's Foundation, Miami, Florida, USA*

Palliative care needs are present at diagnosis (and often before) and change over time.



Ideally, palliative care would be integrated into all care from diagnosis onward.



In the real world, you and your family must be prepared to advocate for a palliative care approach.

SELF-ADVOCACY



**SPEAKING UP
FOR YOURSELF**



**STAYING
INFORMED**



**KNOWING
YOUR RIGHTS**



**FINDING
SUPPORT**



**PROBLEM
SOLVING**



**SELF
DETERMINATION**



**ASKING
FOR HELP**

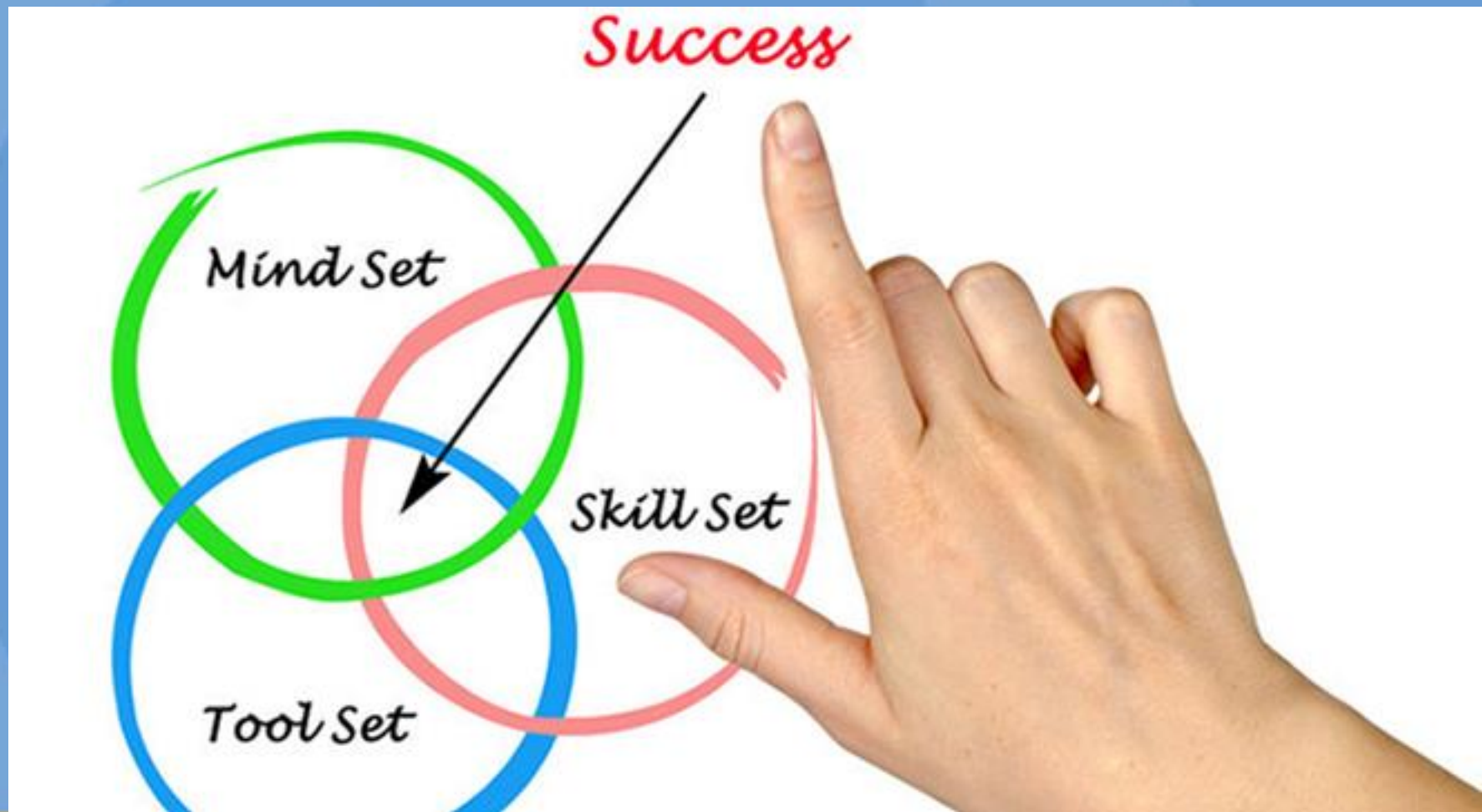
You are part of the healthcare team!

- No one is more invested in your health than you are.
- Activated patients and families get better care.
- You have opportunities to shape the care you receive

“You are braver than you believe, stronger than you seem, and smarter than you think.”

- Winnie the Pooh (A.A. Milne)

Self-care can benefit from a palliative care mindset.



Applying the Palliative Care Mindset to Living with Parkinson's: Reduce Suffering

1. What are your sources of suffering?
 - a. Can you name those things that are toughest for you?
 - b. What options do you have for cure, coping, or compassion?

Cure, Coping, and Compassion

CURE

- Treating a bothersome symptom (e.g., pain, constipation)
- Eliminating a problem (e.g., simplifying your life)

COPING

- Find a style that works for you (e.g., humor, reappraisal, faith, acceptance)

COMPASSION

- Self-kindness, mindfulness, common humanity (From Kristin Neff)

Applying the Palliative Care Mindset to Living with Parkinson's: Increase Joy

2. What are your opportunities for joy?

- a. What strengths, values, loves, and joys do you carry into this illness?
- b. How can you stay connected to these important parts of you you are and what you value to your current situation?
- c. Are there ways to adopt or adapt to stay connected or new opportunities to explore?

Applying the Palliative Care Mindset to Living with Parkinson's: Find Your People

3. Who in your personal and healthcare community can you turn to to share your suffering and celebrate your joy?

- a. On the healthcare side: doctors, nurses, social workers, chaplain, therapists, and more
- b. On the personal side: friends, family, spiritual community, neighbors, support group, and more

**You can get more from
your healthcare team
with a palliative care
skillset and toolset.**



The 5 Pillars of Palliative Care

PILLAR	SKILL	TOOL
1. Nonmotor symptoms	Set the agenda for your visits	Symptom checklist
2. Emotional and spiritual Support	Go outside the medical model	Counseling and peer support
3. Preparing for the future	Start important conversations	Question prompt list
4. Family support	Ask for what you need	Caregiver checklist
5. Specialist palliative care & hospice	Get an extra layer of support	Referral to resources in your community

Make a checklist for your visits.

PILLAR	SKILL	TOOL
1. Nonmotor symptoms	Set the agenda for your visits	Symptom checklist

- ✓ Pain
- ✓ Sleep, fatigue
- ✓ Constipation, urination
- ✓ Depression, anxiety
- ✓ Change in weight or appetite
- ✓ Nightmares, hallucinations, change in personality

*Could any of my symptoms be side effects of medications?

Find help outside of the medical model.

PILLAR	SKILL	TOOL
2. Emotional and spiritual Support	Go outside the medical model	Counseling and peer support

- Chaplain
- Spiritual community
- Psychologist
- Mental health counselor
- Social work
- Support groups
- Friends and family

Let your doctors know what you want to know.

PILLAR	SKILL	TOOL
3. Preparing for the future	Start important conversations	Question prompt list

- What is the best case, worst case, or most likely scenario for how my Parkinson's may progress?
- What symptoms may indicate that my Parkinson's is progressing? (What should I be looking out for?)
- How can my family and I be better prepared for the future?
- I would like to complete paperwork to put my future wishes in writing (e.g., health care proxy, living will, advance directive).

If you're a caregiver, ask for what you need.

PILLAR	SKILL	TOOL
4. Family support	Ask for what you need	Carer checklist

- Self-care
- Emotional, social, and spiritual support
- Being prepared for the future
- Caregiving skills
- Help at home

Ask for referrals to specialists when you need it.

PILLAR	SKILL	TOOL
5. Specialist palliative care & hospice	Get an extra layer of support	Referral to resources in your community

You have the right to request referrals to palliative care and other specialists, as well as second opinions.

**Get a referral
for supportive
or palliative
care if you
need an extra
layer of
support.**



What does specialist palliative care do?

- Help with challenging symptoms like pain and fatigue
- Provide support around difficult but normal emotions (e.g., grief, worry, and frustration)
- Explore spiritual or religious issues—like hopelessness or loss of meaning—associated with having a serious illness
- Provide support for family members and caregivers
- Talk about the big picture, including a road map for the future
- Coordinate care across multiple providers
- Clarify your goals and how your values can drive your care

The Supportive Care Team

- Palliative medicine or neuropalliative care specialist
- Social worker
- Nurse
- Chaplain
- Mental health counselor
- Psychologist
- Home health services

When do you consider a referral for a palliative care specialist?

- Can be at any point in your Parkinson's journey
- Difficult to control nonmotor symptoms (e.g., pain)
- Struggling with difficult emotions (e.g., grief)
- Struggling with severely limited quality of life
- Care partner or family distress or need for more support
- Guidance needed for planning for the future, discussing road map, or prognosis
- Difficulties coordinating care across providers

When do you consider a referral to hospice?

- Your primary goal for care and treatment is comfort.
- You would not want to go to the hospital if you developed pneumonia or other infection.
- You would like to maximize your time at home (or your current residence) and with family/friends.
- You would like an alternative to future ED visits, hospital stays, or calling 911.
- You and your family could benefit from an extra layer of medical support.

You have the power to change care!



Action Steps

- Identify your sources of suffering (what's tough about Parkinson's?) and your opportunities for joy, love, and meaning.
- Find ways to cure (when possible), cope, and have self-compassion.
- Connect with people in healthcare and in your community who can help you live more fully.
- Prepare for your visits with healthcare professionals and don't be afraid to ask for more support.