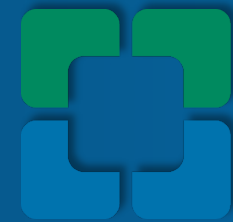




Cleveland Clinic Palliative Care for PD



March 16th, 2023

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Defining
palliative care
for Parkinson
disease

What is palliative care?





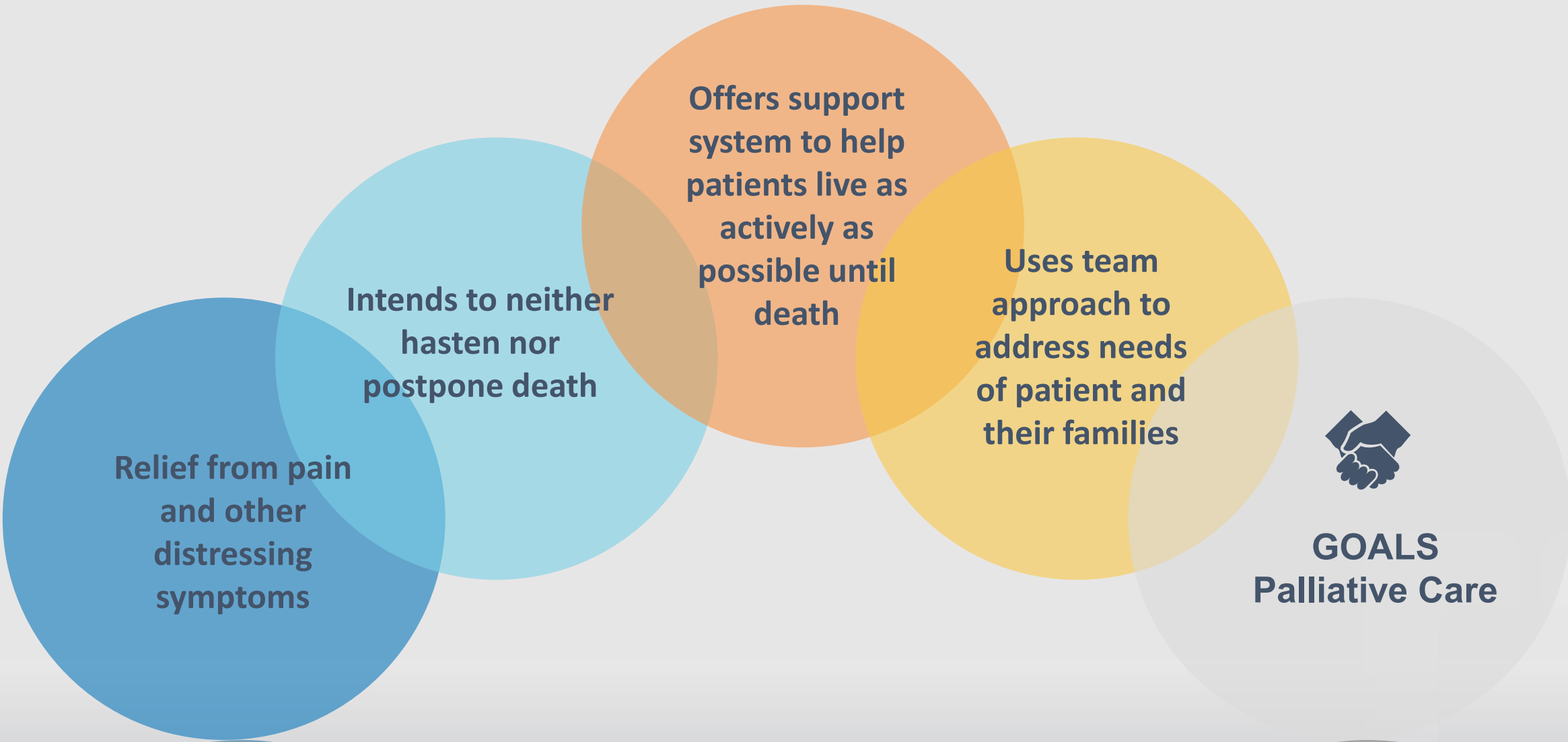
Palliative Care

Palliative care is “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.”





Palliative Care - Goals



Palliative Care and Hospice Care: What Is the Difference?

The phrases *palliative care* or *hospice* can make anyone feel unsettled and anxious. However, knowing what these terms mean and how they can help a person with Parkinson's disease (PD) and a care partner can bring calmness and often an extra layer of support.

PALLIATIVE CARE

Helps people with PD and care partners better manage any stage of PD

Can be provided alongside other therapies

Provides proactive support and guidance to prepare patient and family for the future



IN COMMON

Helps ensure better quality of life and provide comfort

Option for those with advanced PD

Helps care partners and families

Care team can include doctors, nurses, social workers, nutritionists, chaplains and therapists

Generally eligible with Medicare, Medicaid and insurance

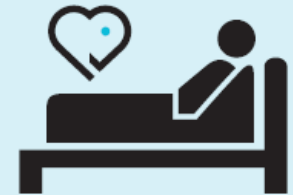
Addresses physical symptoms (like pain management), emotional, social and spiritual needs for person with PD and care partner

HOSPICE CARE

Provides maximum amount of dignity and comfort during end of life

Care can occur at residence

Works with treating physician



CARE-PD Clinic

Comprehensive Assessment and treatment clinic for Parkinson's disease



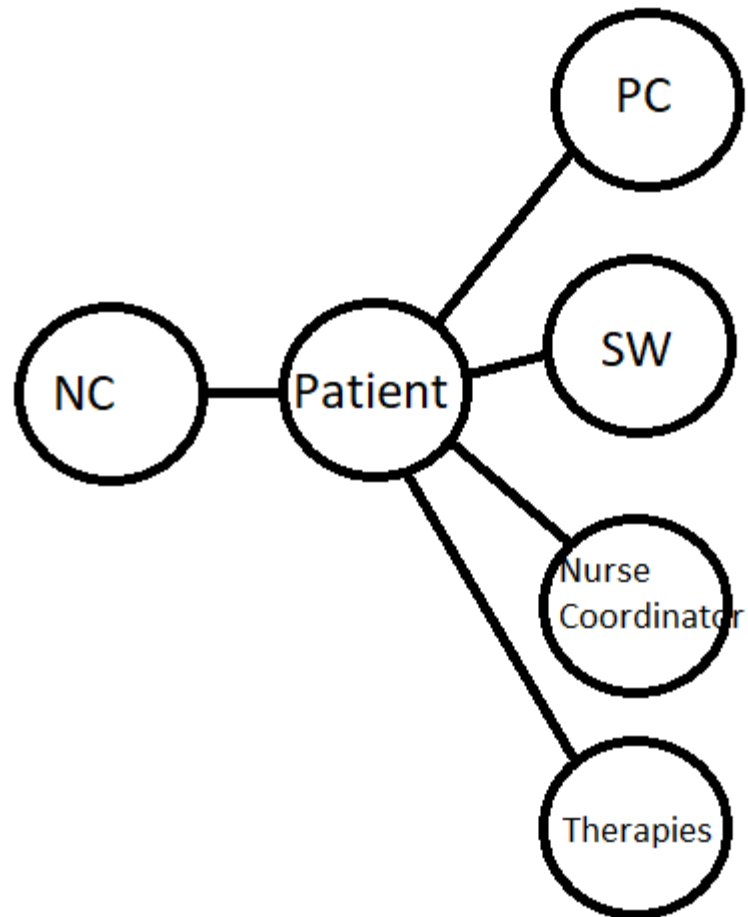
CARE-PD Clinic

- Interdisciplinary clinic with social work (Kayla St John), palliative care (Dr. Renato Samala) and neurology (Dr. Adam Margolius)
- All three providers see the patient and caregiver together in an hour-long visit (thirty minutes for follow ups)
- The clinic started in 2020 one half-day per month, increased to two half-days per month in 2021

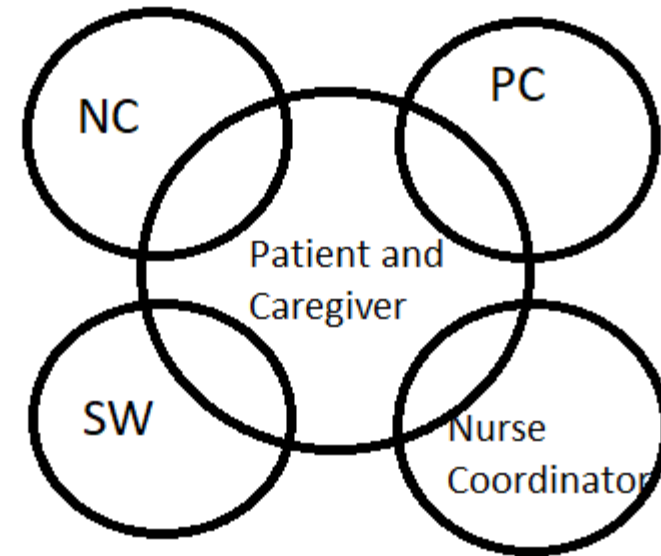


CARE-PD Clinic

A



B



What services do we provide?

- We can assist with non-motor symptom burden, especially pain control, but also constipation, confusion, depression, low blood pressure, etc
- Assistance with obtaining additional help/resources, including home equipment, home therapies
- Help with planning for the future, including discussions of goals of care, assistance with transitions from home to nursing facility, or referrals for hospice (home or inpatient)
- Assessment for caregiver burden and provide support for caregiver



Who should be referred to the CARE-PD clinic?

Brief Needs Assessment Tool (BNAT) (A No for #1 or Yes for #'s 2-9 Identifies A Palliative Need)

1. Would you be surprised if this patient passed away within the next year?	Y	N
2. Does the patient or care partner have a severely reduced quality of life because of their illness?	Y	N
3. Does the patient have motor or non-motor symptoms that are resistant to treatment, such as postural instability, pain, fatigue, constipation, or dysphagia?	Y	N
4. Is the patient experiencing mood problems (e.g. depression, anxiety, apathy) or behavioral issues (e.g. hallucinations, delusions, agitation)?	Y	N
5. Is the care partner struggling with feeling overwhelmed?	Y	N
6. Is the patient or care partner struggling with difficult emotions such as guilt, grief, or anger?	Y	N
7. Is the relationship between the patient and care partner strained due to illness?	Y	N
8. Does the patient or care partner have spiritual or existential concerns such as loss of hope or feeling demoralized?	Y	N
9. Does the patient or care partner have significant concerns or worries about the future?	Y	N

Who should be referred to the CARE-PD clinic?

- Troublesome or difficult to manage non-motor symptoms, especially chronic pain
- Caregiver strain/burnout
- Questions about planning for the future, or about death/dying

- *We are happy to see patients with an atypical syndrome (MSA, PSP, DLB etc.)



Who maybe shouldn't be referred to the CARE-PD clinic?

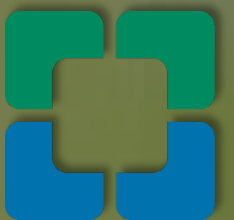
- Patients who may be better served by psychiatry referral (severe depression/anxiety in absence of other disabling non-motor symptoms)
- Patients who live out of state or considerable distance away
- Patient hoping for a second opinion on diagnosis





Palliative care
and Parkinson
disease

Management strategies for common issues in late-stage PD



Bothersome symptoms in early PD

TABLE 2. Rank of the 24 most bothersome PD related symptoms/conditions in 92 early patients with up to 6 yr of disease duration

Rank	Symptom/condition	Total score	First choice %	Second choice %	Third choice %	3-Choice complaint prevalence (%)
1	Slowness	112	32.6	5.4	13.0	51.1
2	Tremor	101	29.3	8.7	4.3	42.4
3	Stiffness	76	6.5	26.1	10.9	43.5
4	Pain	50	9.8	9.8	5.4	25.0
5	Loss of smell/taste	30	3.3	9.8	3.3	16.3
6	Mood	28	4.3	6.5	4.3	15.2
7	Handwriting	18	2.2	3.3	6.5	12.0
8	Bowel problems	17	2.2	3.3	5.4	10.9
9	Sleep	15	2.2	4.3	1.1	7.6
10	Appetite/weight	13	0.0	3.3	7.6	10.9

Bothersome symptoms in late PD

TABLE 3. Rank of the 24 most bothersome PD related symptoms/conditions in 173 advanced patients with more than 6 yr of disease duration

Rank	Symptom/condition	Total score	First choice %	Second choice %	Third choice %	3-Choice complaint prevalence (%)
1	Fluctuating response to medication	115	15.0	8.1	5.2	28.3
2	Mood	96	7.5	12.1	8.7	28.3
3	Drooling	85	10.4	6.9	4.0	21.4
4	Sleep	83	9.8	5.2	8.1	23.1
5	Tremor	67	8.1	5.2	4.0	17.3
6	Pain	60	6.4	5.8	4.0	16.2
7	Bowel problems	46	4.0	4.0	6.4	14.5
8	Urinary problems	40	2.9	5.2	4.0	12.1
9	Falls	39	4.0	4.0	2.3	10.4
10	Appetite/weight	36	2.3	4.6	4.6	11.6

Patients needs

Edmonton Symptom Assessment System for PD (ESAS-PD)

**Edmonton Symptom Assessment System:
Numerical Scale**
Regional Palliative Care Program

Please circle the number that best describes:

No pain 0 1 2 3 4 5 6 7 8 9 10 Worst possible pain

Not tired 0 1 2 3 4 5 6 7 8 9 10 Worst possible
tiredness

Pain, tiredness, nausea, depressed, anxious, drowsy, anorexia, wellbeing,
SOB, stiffness, constipation, dysphagia, confusion

Pain

- ~80% of PD patients experience some form of pain regularly, often directly or indirectly related to PD.
- 1/6 patients with advanced PD say pain is one of their three most bothersome symptoms.
- Caregivers often feel pain is poorly managed at the end of life.



Other non-motor symptoms

Symptom type	Examples
Autonomic symptoms	Orthostatic hypotension, urinary dysfunction, drooling, constipation
Mood and cognitive symptoms	Anxiety, depression, apathy, confusion, hallucinations, cognitive impairment
Sleep disorders	Insomnia, excessive daytime sleepiness, REM sleep behavior disorder (RBD)



Medication Burden

- Can affect quality of life due to increased frequency of medication administration, drug interactions, financial burden, caregiver burden
- Simplify/streamline regimens
- Try non-pharmacologic alternatives



Caregiver Needs

- Caregiver physical and emotional help is vulnerable in late stage disease
- Patient's quality of life is heavily dependent on their caregiver's health and well-being
- Resources such as local support groups, or home health aide can alleviate caregiver strain

Key Takeaways

- Palliative care plays an important role in all stages of PD
- Non-motor symptoms are especially troublesome in late-stage PD
- Specialty care (like the CARE-PD clinic) can help





Every life deserves world class care.