The Role of Palliative Care in Parkinson's Disease

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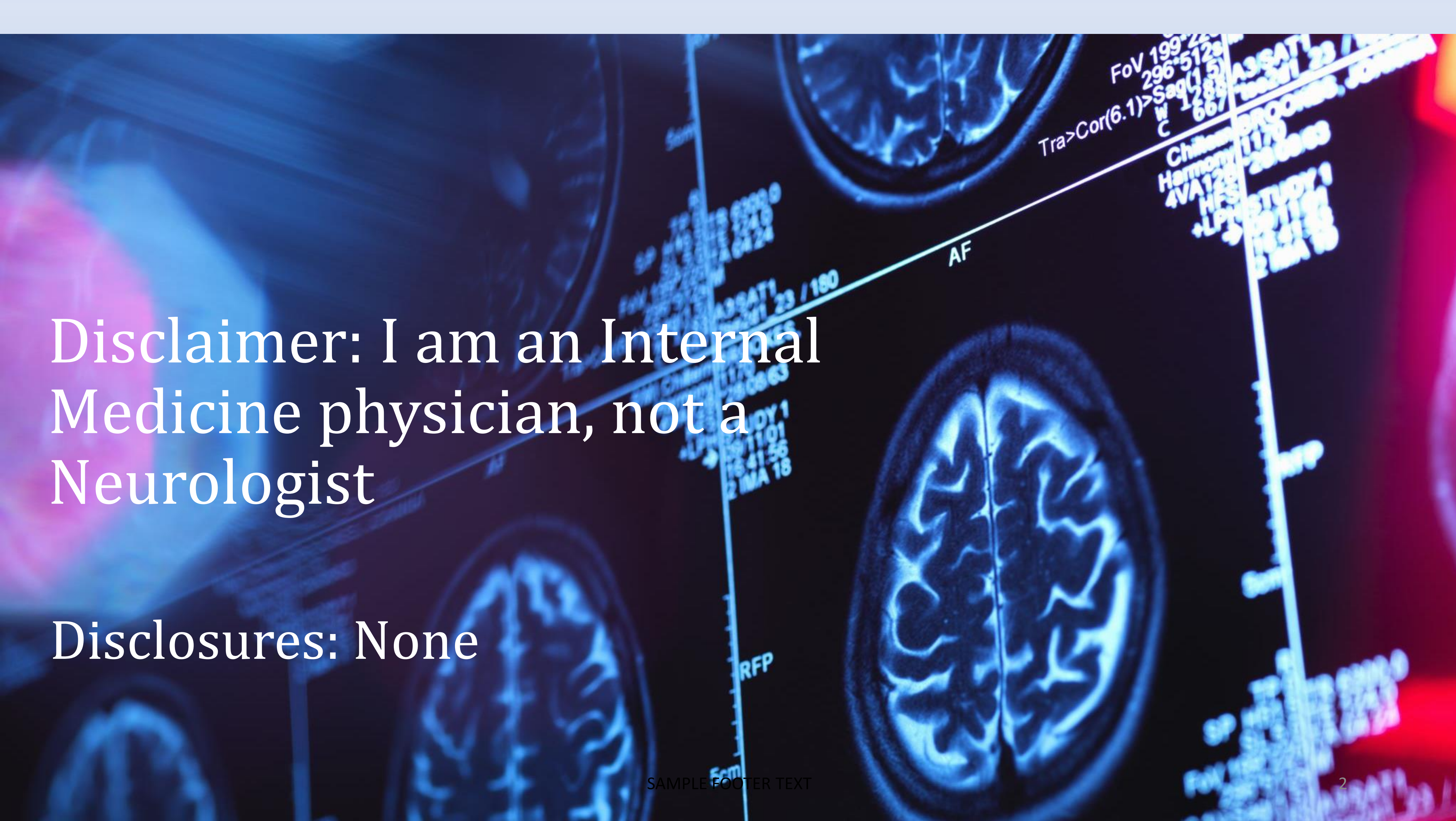
Disclaimer: I am an Internal Medicine physician, not a Neurologist
Disclosures: None
AF
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Objectives

1.) Palliative Care

- Define and Compare Palliative Care to Hospice Care
- The Roles of the Palliative Care Team
- The Importance of Advance Directives

2.) Parkinson's Disease

- The History of Parkinson's Disease
- Presentation of Parkinson's Disease
- Palliation of Common Parkinson's Symptoms

3.) End Stage Parkinson's Disease and Hospice

Objective 1

Palliative Care

The Definition of Palliative Care

"Palliative care is specialized medical care for people living with a serious illness. Patients in palliative care may receive medical care for their symptoms, or palliative care, along with treatment intended to cure their serious illness."

NIH

National Institute on Aging

Palliative Care was recognized as a medical specialty in 1974

Why Palliative Care?

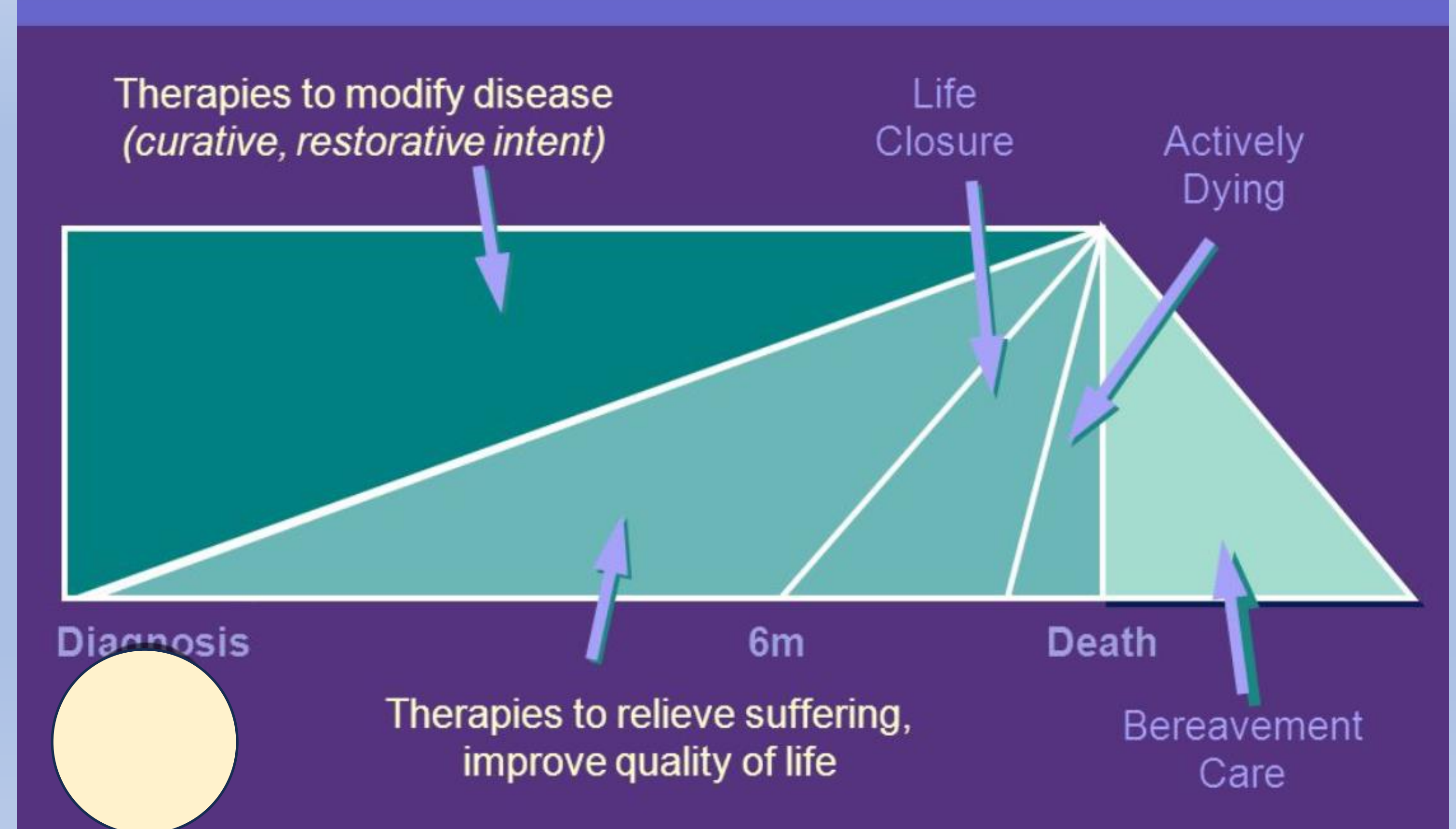
Why Palliative Care?

Common diagnoses followed:

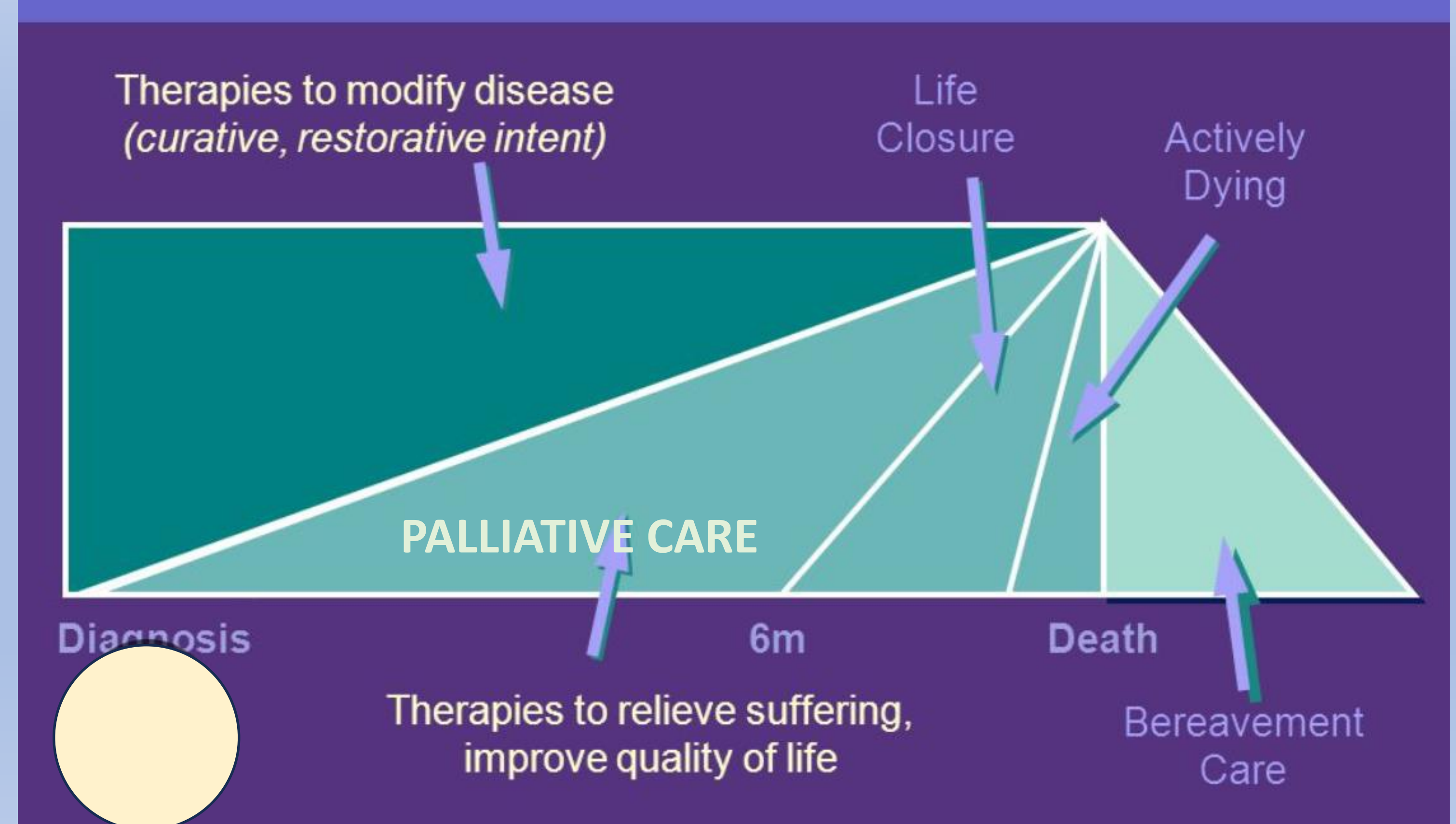
- **Cancer**
- **Cardiac disease such as Congestive Heart Failure**
- **Chronic Obstructive Pulmonary Disease (COPD)**
- **Kidney failure**
- **Alzheimer's Disease**
- **Parkinson's Disease**
- **Amyotrophic Lateral Sclerosis (ALS)**

Text

Diagnosis



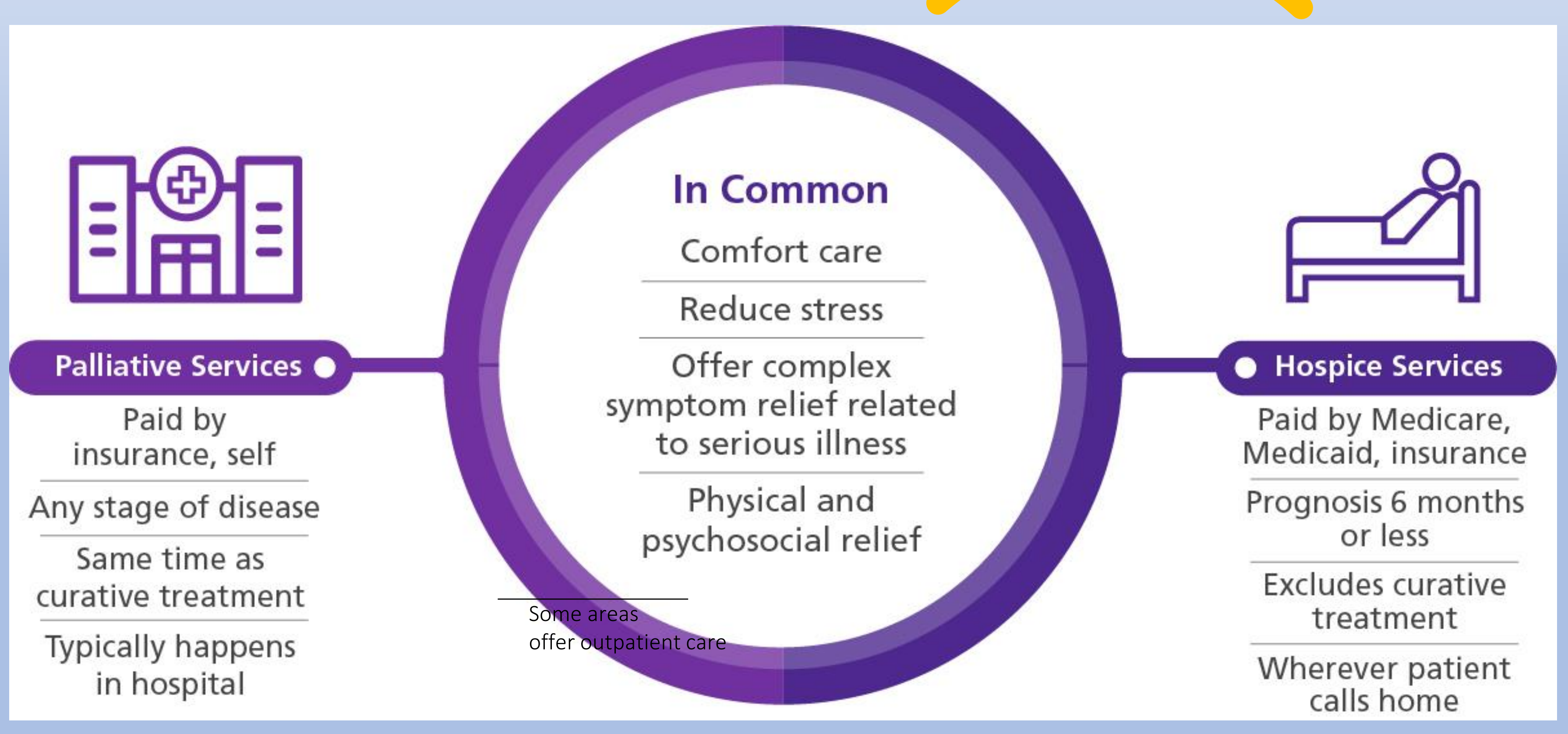
TIME



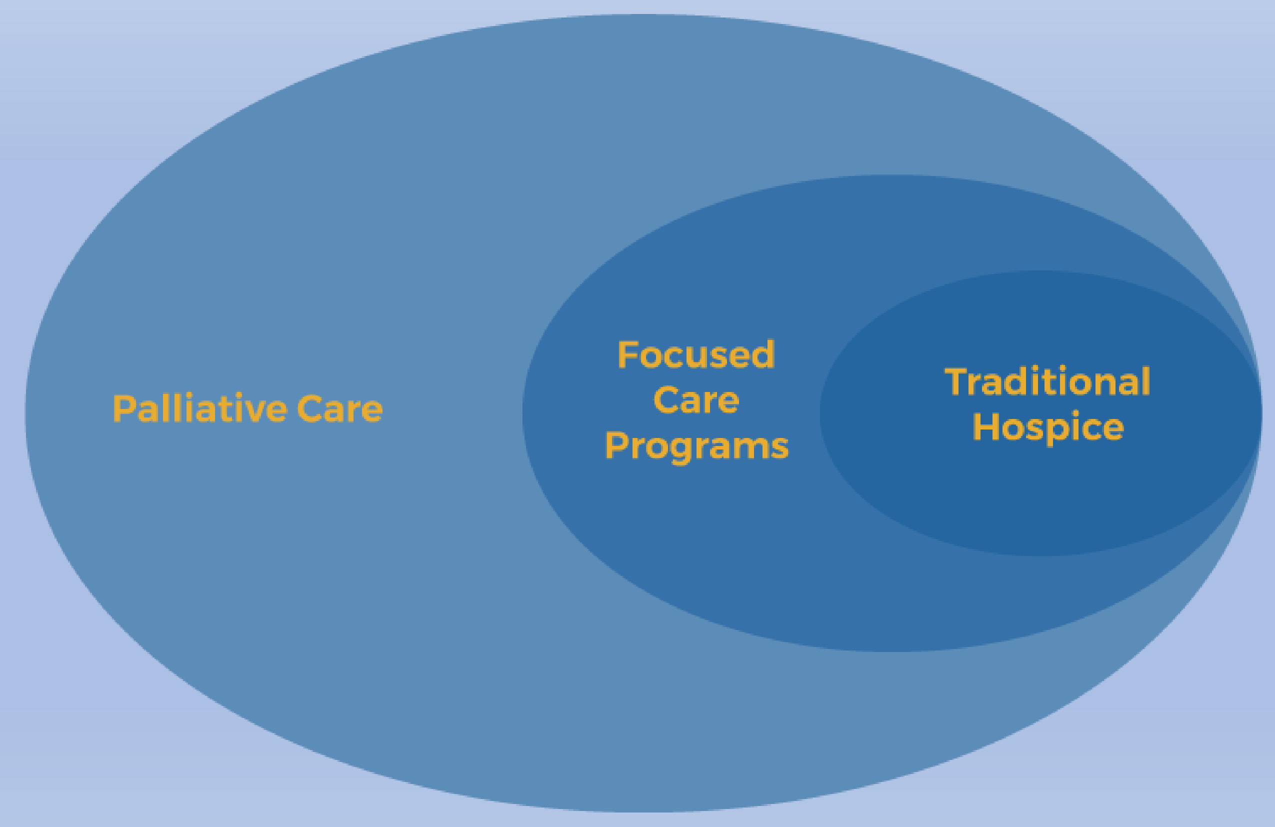
Diagnosis

TIME

Comparison of Palliative Care and Hospice Care



The overall goal for both is to provide comfort



All Hospice is Palliative Care but not all Palliative Care is Hospice

When is the right time for Palliative Care?

Symptoms of chronic disease often worsen over time.

Most palliative care referrals occur when patients need more assistance with symptom management.

Patients can pursue curative treatments while receiving palliative care.

Palliative care can be offered at any age or stage of disease.

The Palliative Care Team

The Palliative Care team consists of specially trained doctors, advanced practice professionals, nurses, social workers, volunteers, and spiritual care providers.

The team works alongside the patient's primary care provider to address symptoms.

Palliative care provides an additional layer of support to the patient and patient's loved ones.

What can I expect from Palliative Care?

Treatment plan

Education

Symptom management

Caregiver support

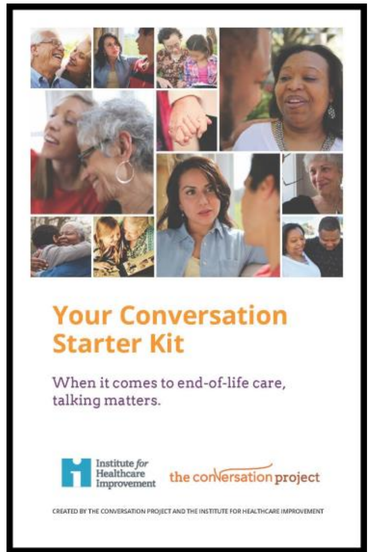
Goals of care

What can I expect from Palliative Care?

What can I expect from Palliative Care?

Advanced Directives

MAKE YOUR WISHES KNOWN



LIVING WILL

This document is a preliminary measure taken in case there ever comes a time when you can no longer communicate your health care wishes to your doctors. The Living Will allows you to tell your health care providers your preferences for end of life treatment.

This form was completed and signed on ____ day of ______________, 20____.

Health Care Directive

I, ______________, with a street address of ______________, City of ______________, County of ______________, State of ______________, with the last four (4) digits of my social security number (SSN) being xxx-xx-______ (Hereinafter may be referred to as the 'Principal') desire to advise my doctors and medical providers of my wishes for my health care in the event I am not able to communicate my wishes.

1) *LIFE SUPPORT*:

I desire that my doctor make a concerted effort to return me to an acceptable quality of life using then available treatments and therapies. However, if my quality of life becomes unacceptable as I have defined below and my doctors have determined that my condition will not improve (is irreversible), I direct that all treatments that extend my life be withdrawn.

An unacceptable quality of life means (initial and check all that apply):

______ ☐ Chronic coma or persistent vegetative state.
______ ☐ No longer able to communicate my needs.
______ ☐ No longer able to recognize family or friends.
______ ☐ Total dependence on others for daily care.
______ ☐ Other: ______________________

Initial and check *only* one:

______ ☐ Even if I have the quality of life described above, I still wish to be treated with food and water by tube or intravenously (IV).
______ ☐ If I have the quality of life described above, I do NOT wish to be treated with food and water by tube or intravenously (IV).

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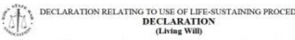
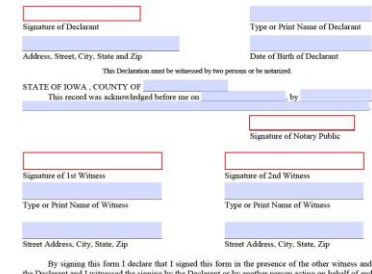

DECLARATION RELATING TO USE OF LIFE-SUSTAINING PROCEDURES

DECLARATION
(Living Will)

If I should have an incurable or irreversible condition that will result either in death within a relatively short period of time or a state of permanent unconsciousness from which, to a reasonable degree of medical certainty, there can be no recovery, it is my desire that my life not be prolonged by the administration of life-sustaining procedures. If I am unable to participate in my health care decisions, I direct my attending physician to withhold or withdraw life-sustaining procedures that merely prolong the dying process and are not necessary to my comfort or freedom from pain.

YES ___ NO ___ In the event that medical professionals determine that I may be an organ donor, I agree to the use of life-sustaining procedures, including a ventilator, for the sole purpose and time period required to complete the organ donation. Nothing in this paragraph shall be construed to expand or detract from the laws related to anatomical gifts as outlined in the Iowa Code, Chapter 142C. The purpose of this paragraph is to practically and medically make organ donation possible.

Signed on ______________.


Signature of Declarant — Type or Print Name of Declarant

Address, Street, City, State and Zip — Date of Birth of Declarant

This Declaration must be witnessed by two persons or be notarized.

STATE OF IOWA , COUNTY OF ______________
This record was acknowledged before me on ______________, by ______________.

Signature of Notary Public

Signature of 1st Witness — Signature of 2nd Witness

Type or Print Name of Witness — Type or Print Name of Witness

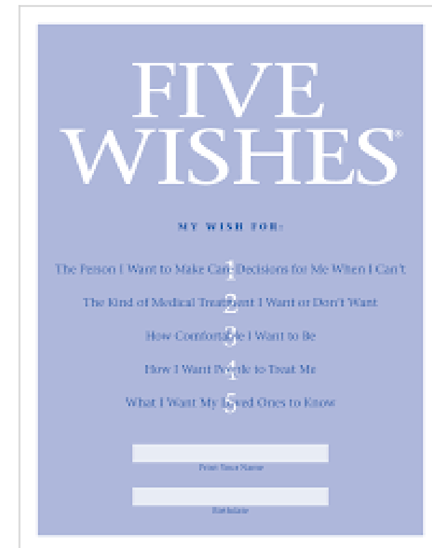
Street Address, City, State, Zip — Street Address, City, State, Zip

By signing this form I declare that I signed this form in the presence of the other witness and the Declarant and I witnessed the signing by the Declarant or by another person acting on behalf of and at the Declarant's direction.

(IMPORTANT: PLEASE SEE NOTES AS TO USE ON REVERSE SIDE)

The Iowa State Bar Association 2021 — Form No. 122, Declaration Relating to Use of Life Sustaining Procedures, Revised January 2016

freeforms



HIPAA PERMITS DISCLOSURE OF IPOST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Iowa Physician Orders for Scope of Treatment (IPOST)

First follow these orders, **THEN** contact the physician, nurse practitioner or physician's assistant. This is a medical order sheet based on the person's current medical condition and treatment preferences. Any **section not completed implies full treatment for that section.** Everyone shall be treated with dignity and respect.

Last Name
First/Middle Name
Date of Birth

A (Check one) — **CARDIOPULMONARY RESUSCITATION (CPR):** Person has no pulse **AND** is not breathing.
☐ CPR/Attempt Resuscitation
☐ DNR/Do Not Attempt Resuscitation

B (Check one) — **MEDICAL INTERVENTIONS:** Person has a pulse **AND/OR** is breathing.
☐ **COMFORT MEASURES ONLY** Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. ***Patient prefers no transfer** to hospital for life-sustaining treatment.* ***Transfer** if comfort needs cannot be met in current location.*
☐ **LIMITED ADDITIONAL INTERVENTIONS** Includes care described above. Use medical treatment, cardiac monitor, oral/IV fluids and medications as indicated. **Do not** use intubation, or mechanical ventilation. May consider less invasive airway support (BiPAP, CPAP). May use vasopressors. ***Transfer** to hospital if indicated, may include critical care.*
☐ **FULL TREATMENT** Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation and cardioversion as indicated. ***Transfer** to hospital if indicated. Includes critical care.*
Additional Orders: ______________________

C (Check one) — **ARTIFICIALLY ADMINISTERED NUTRITION Always offer food by mouth if feasible.**
☐ No artificial nutrition by tube.
☐ Defined trial period of artificial nutrition by tube.
☐ Long-term artificial nutrition by tube.

D — **MEDICAL DECISION MAKING**

Directed by: (listed in order of Iowa Code/Statute for Priority of Surrogates; check only one)	**Rationale for these orders:** (check all that apply)
☐ Patient	☐ Advance Directives
☐ Durable Power of Attorney for Health Care	☐ Patient's known preference
☐ Spouse	☐ Limited treatment options
☐ Majority of Adult Children	☐ Poor prognosis
☐ Parents	☐ Other: ______________
☐ Majority rule for nearest relative	
☐ Other: ______________	

Physician/ARNP/PA signature (mandatory)	Print Physician/ARNP/PA Name	Date	Phone Number

Patient/Resident or Legal Surrogate for Health Care Signature as identified above (mandatory)	Date

SEND IPOST WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

DOCUMENT THAT IPOST FORM WAS TRANSFERRED WITH PERSON

Objective 2

Parkinson’s Disease

The History of Parkinson's Disease

As long as 4500 years ago, an ancient Indian medical system described a shaking, muscular movement disorder. The plant *Mucuna Pruriens* treated these symptoms and was later discovered to contain levodopa.

1817

James Parkinson described Parkinson's Disease in his essay Shaking Palsy

1912

Frederick Lewy reported neuronal cytoplasmic inclusions in the brain

1950

Investigators discovered the importance of dopamine and its depletion from the basal ganglia

Four Stages of Parkinson's Disease

Tremor in arms, hands, legs, jaw or head

Muscle stiffness, where muscle remains contracted for a long time (rigidity)

Slowness of movement (bradykinesia)

Impaired balance and coordination, sometimes leading to falls

Changes of dopamine in the brain may occur years before the onset of symptoms.

Most people develop Parkinson's symptoms after age 60.

Approximately 5 - 10% experience symptoms before the age of 50.

Symptoms of Parkinson’s Disease

Early symptoms are subtle and occur gradually.

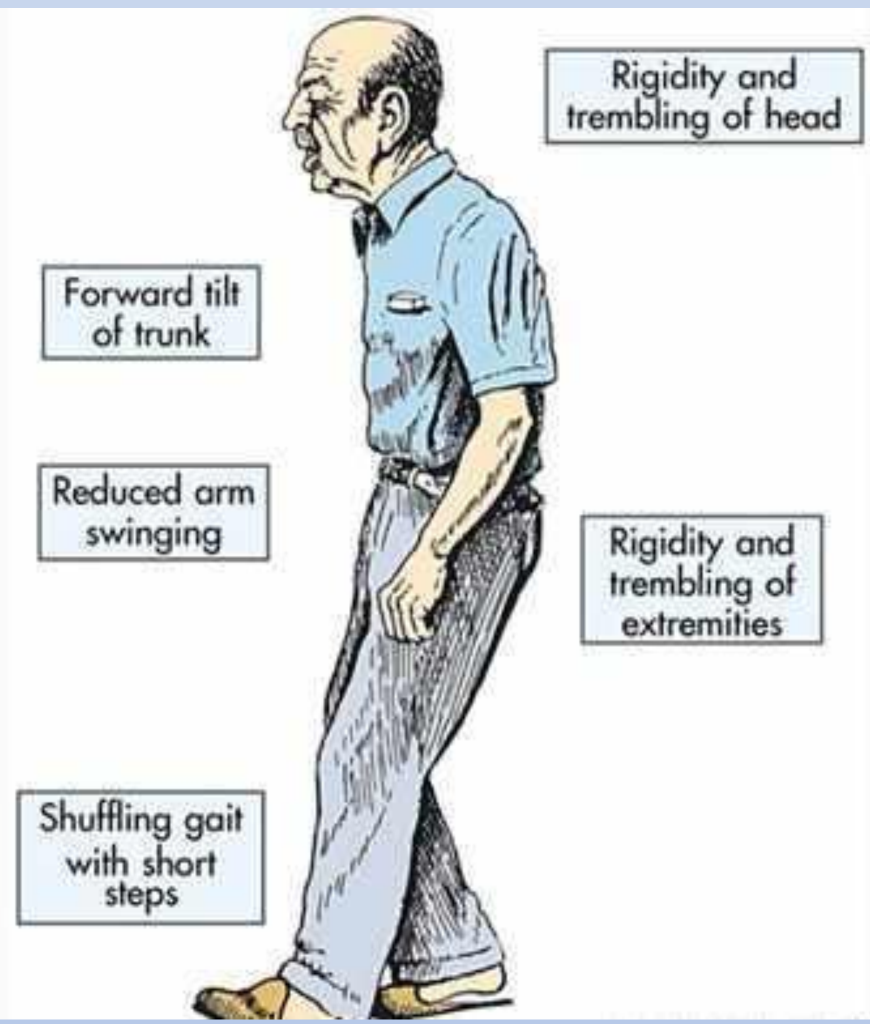
Changes in handwriting, speech, facial animation, or difficulty getting out of a chair may be presenting signs.

Gait is often affected. Patients experience difficulty initiating movement. Parkinsonian gait involves small, quick steps, leaning forward, and reduced swinging movement of arms.

Changes in cognition including problems with memory or attention may occur.

The rate of disease progression and symptoms vary from person to person.

Parkinsonian Gait



Diagnosis of Parkinson's Disease

- Typically based on symptoms
- Improvement of symptoms with trial of medication
- No blood tests required for diagnosis
- Some causes are hereditary; Rare genetic variants
- Exposure to toxins as a cause is a working theory
- Male predominance

Some other diseases may present with similar symptoms, so it is important to get an accurate diagnosis as soon as possible

Treatment for Parkinson's Disease

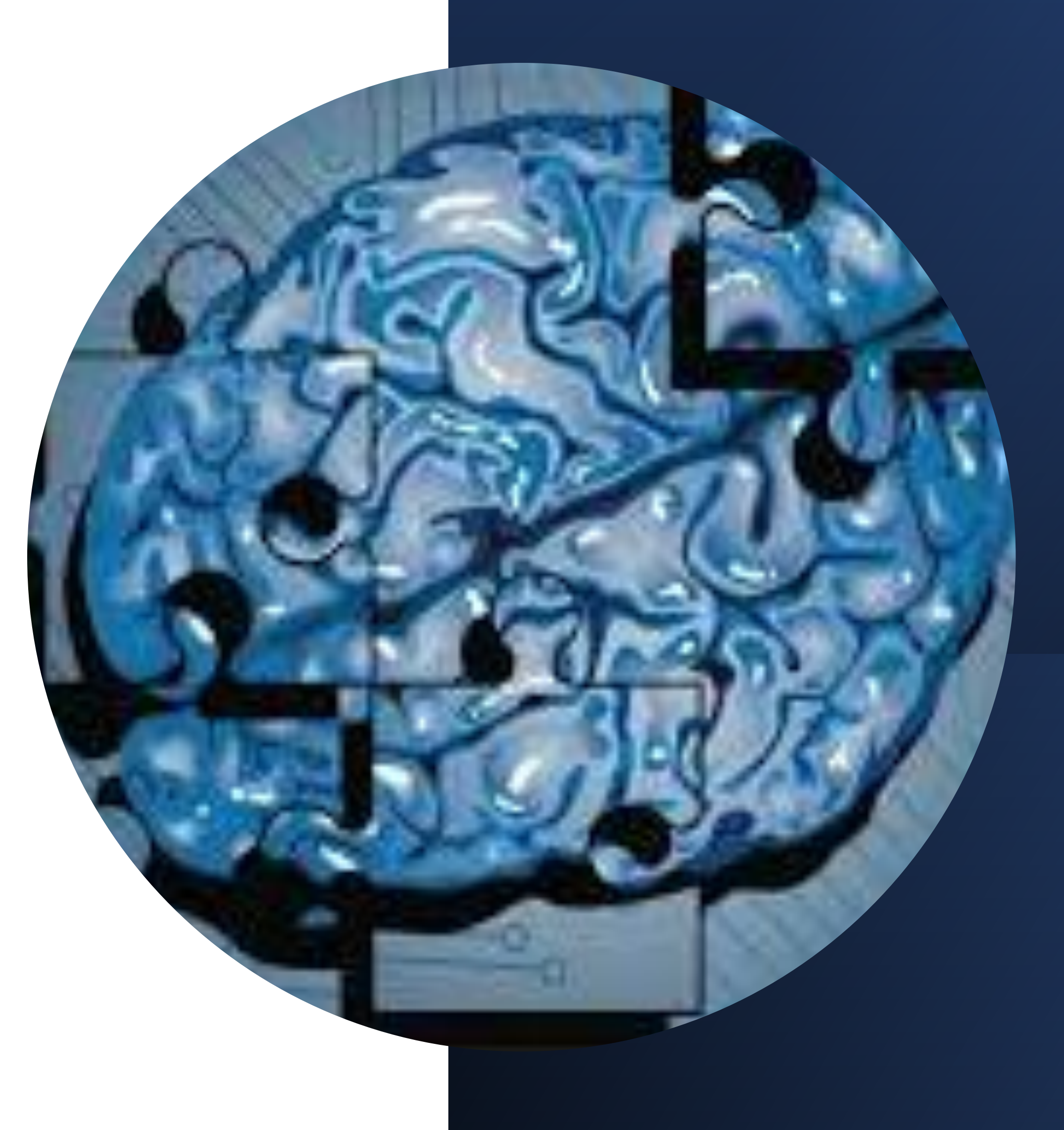
- There is no cure for Parkinson's Disease
- Medicines, surgical treatment, and other therapies can palliate symptoms
- Symptoms are broken down into motor and non-motor symptoms
- Life expectancy is 7 – 15 years following diagnosis

Management of Common Parkinson’s Disease Symptoms

Motor symptoms (rigidity, tremor, bradykinesia):

Levodopa is commonly used to help with movement symptoms. Additional medications may be added to address other various involuntary movements.

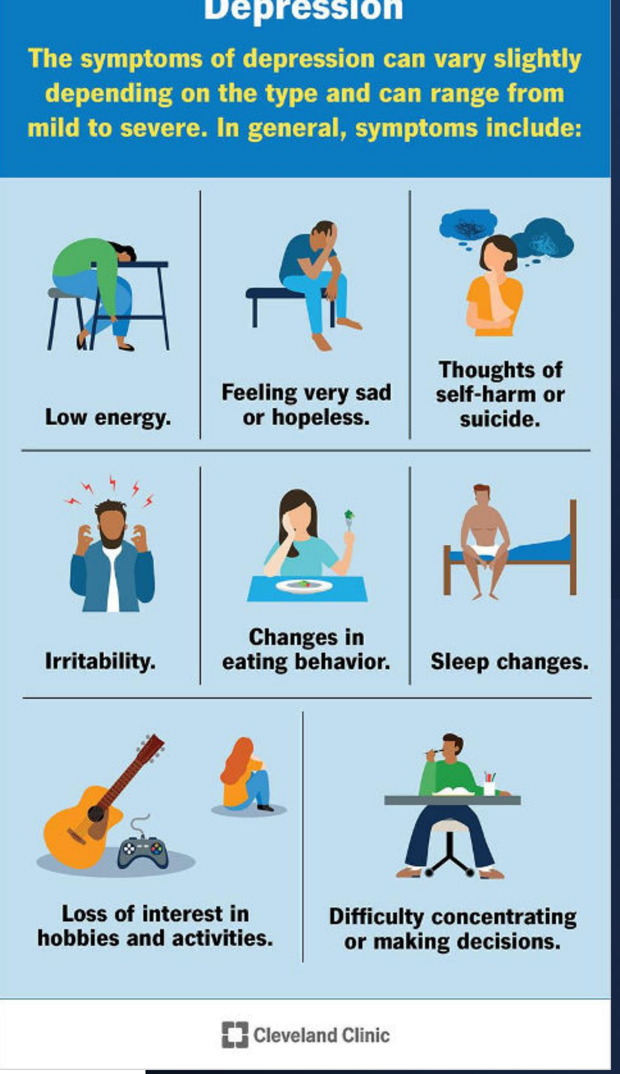
Physical and occupational therapies can help with balance and walking problems.



Management of Common Parkinson’s Disease Symptoms

Mood disorders (Depression and Anxiety):

Cognitive Behavioral Therapy and/or Antidepressants such as a Selective Serotonin Reuptake Inhibitor (SSRI) can treat symptoms.



Management of Common Parkinson’s Disease Symptoms

Swallow and speech difficulties:

Speech therapy can be employed to maintain speech volume and voice quality. Speech therapy and dietary modification may aid those with swallow dysfunction.

Medications can be used to assist with salivation.

Management of Common Parkinson’s Disease Symptoms

Sleep disturbance:

Sleep can be affected by adjusting activity, addressing good sleep hygiene, or using medications to combat sleep interruptions.

- We advise against the use of diphenhydramine for sleep due to risk of increased side effects.

Management of Common Parkinson’s Disease Symptoms

Bowel and bladder issues :

Parkinson’s Disease can affect the nerves and muscles of the bowel and bladder. Diet, lifestyle, physical activity, and medications can manage symptoms.

Management of Common Parkinson's Disease Symptoms

Cognitive changes:

Difficulty with attention/planning, drawing, or facial recognition are symptoms of executive functioning loss. Cholinesterase inhibitors may be prescribed to improve symptoms.

Hallucinations may occur later in disease process.

Medications used to treat Parkinson's motor symptoms may worsen hallucinations.

Management of Common Parkinson's Disease Symptoms

Pain:

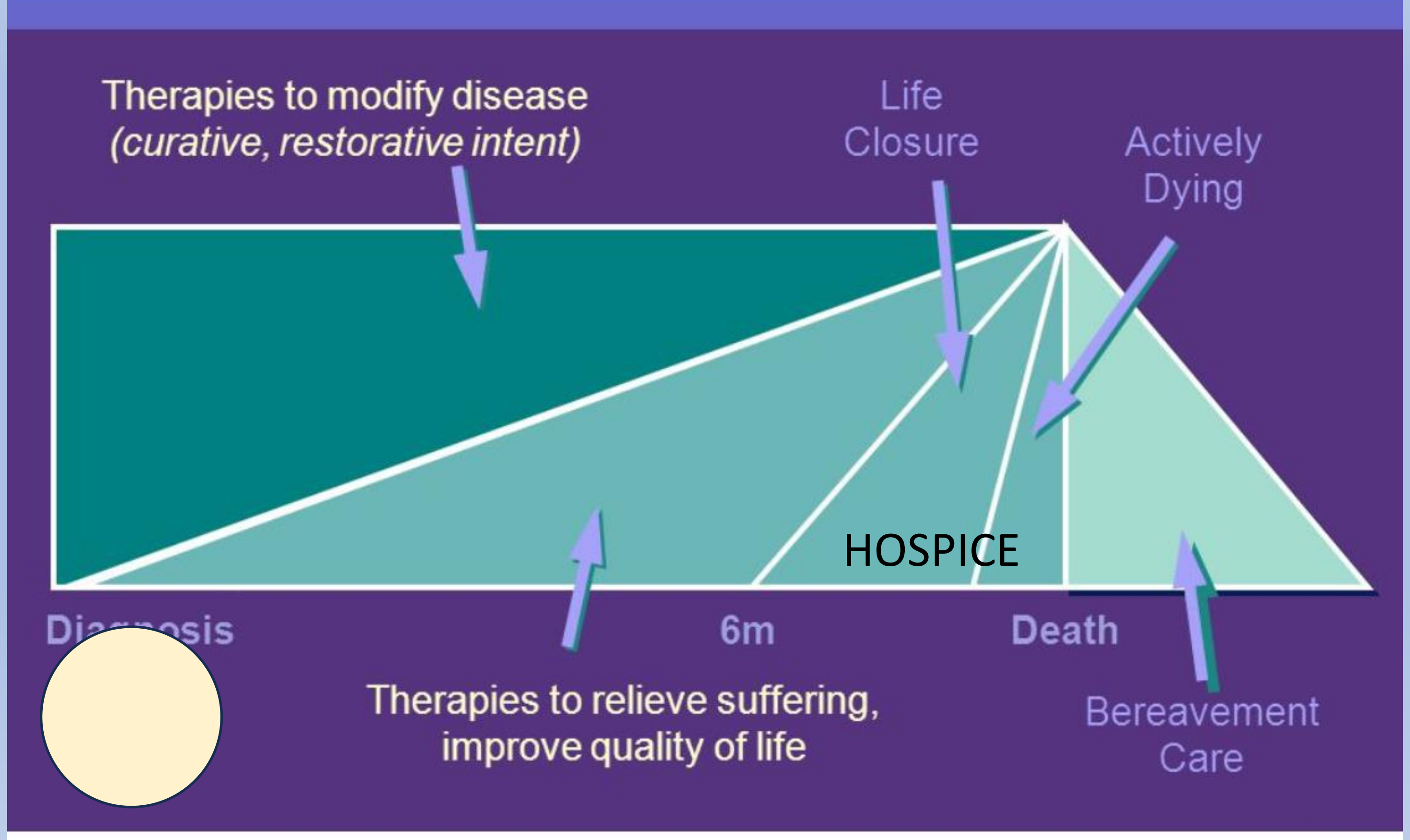
Pain is often under-recognized. Anti-inflammatories, botulinum toxin injections, deep brain stimulation, and physical and occupational therapies can aid pain symptoms.

Opiates are reserved as a last resort.

Objective 3

End Stage Parkinson’s Disease and Hospice

The continuum of palliative care



Hospice is end of life care

Goals change to comfort focused; Quality of life over quantity of life

Two providers certify that life expectancy is 6 months or less “should disease run its normal course”

Hospice is a medical benefit and is free of charge to anyone who qualifies

Hospice team comes to the patient

The Hospice Team

Physician

Pharmacist

Advanced Practice Provider

Social Worker

Spiritual Care

Nurse

Hospice Aides

Volunteer

Other disciplines as needed (includes physical or occupational therapy; music, pet, or art therapy; massage, etc.)

Final Stages of Parkinson's Disease

Nutrition impairment

Inability to maintain fluid/caloric intake

Refusal of artificial feeding

Advanced dementia

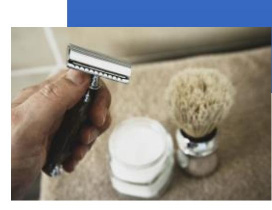
Incontinence

Limited speech

Inability to ambulate or sit up independently

Motor symptoms poorly responsive to medications

Inability to provide self care

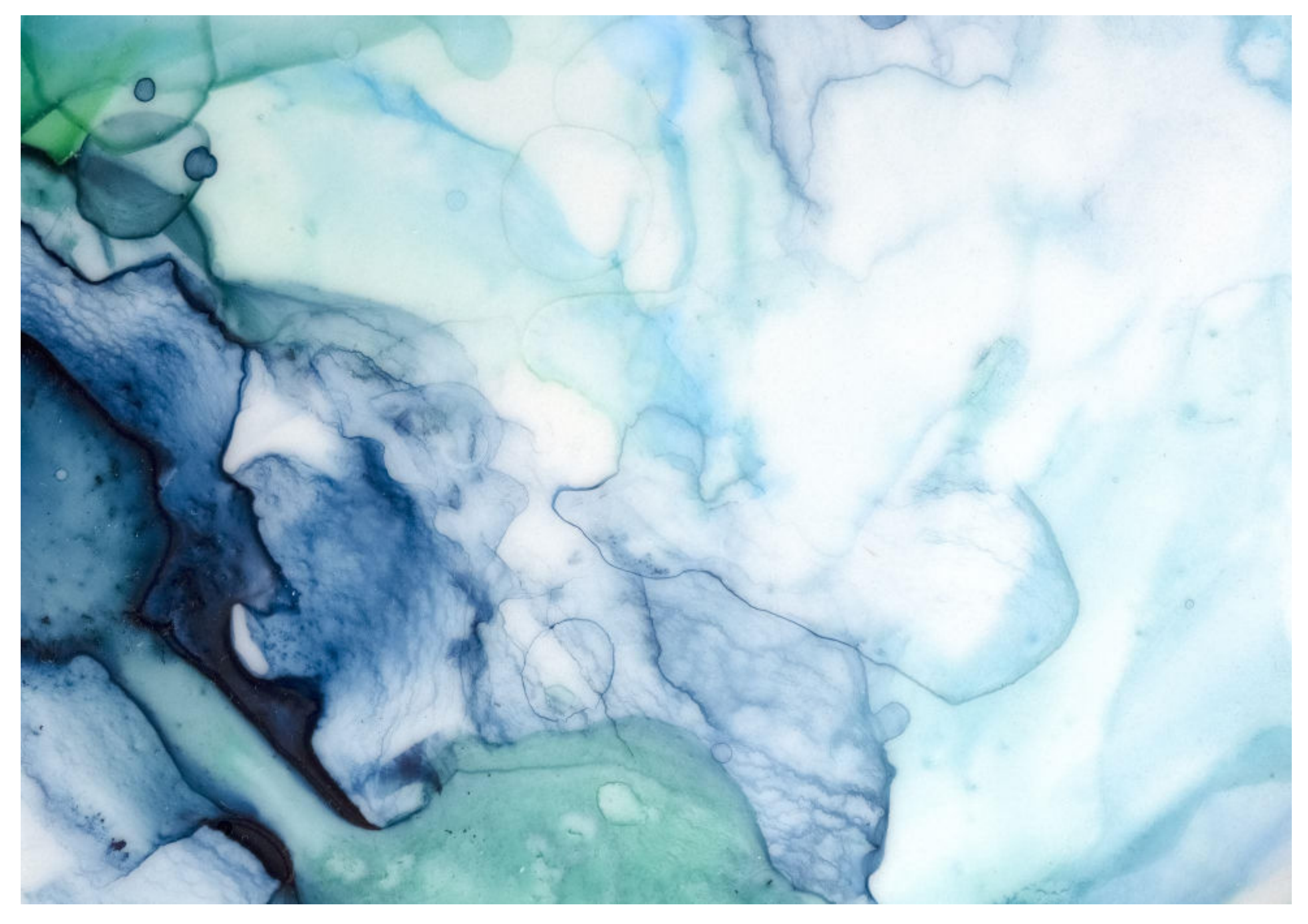


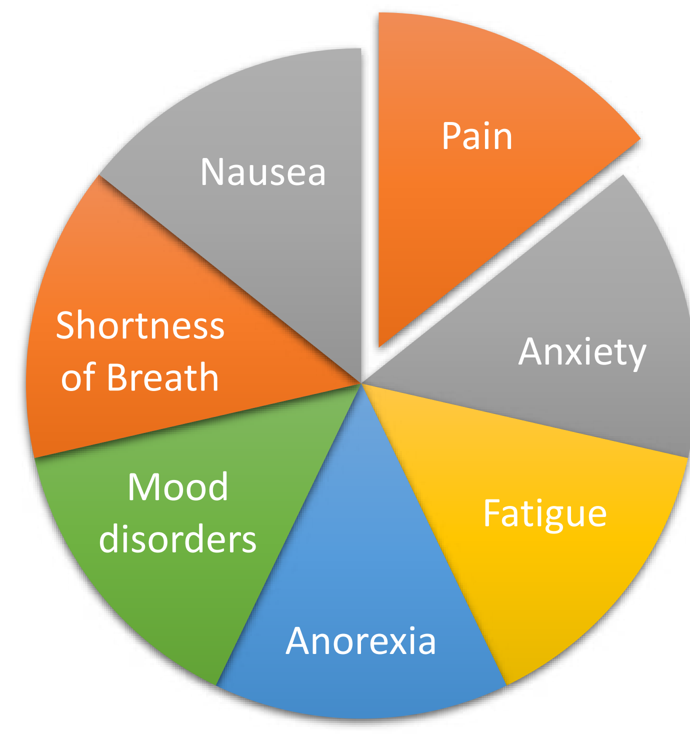
Life threatening complications such as falls, infections, or pressure injuries

These conditions may prompt a hospice referral

Parkinson's Disease: Symptoms at End of Life

The hospice team utilizes medications and other treatments to alleviate these symptoms and provide comfort





Outpatient Palliative Care in Siouxland

THANK YOU!!