

The Impact of Caregiving – Caring for the Parkinson's Caregivers

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November 3, 2023

Green Valley Parkinson's Support Group

Arizona

Objectives: To discuss:

1. The pathophysiology behind the symptoms with greatest impact on caregivers of people with Parkinson's Disease (Movement Disorders).
2. The physiology of stress and accelerated aging of caregivers.
3. Discuss effective strategies to help caregivers.

Caregiving:

~ 48 million caregivers provide *unpaid* care to an adult or child in US in a year

~ 35 million provide care to an adult 50 or older

~ 1 million people living with Parkinson's – most caregiving is unpaid.

National Alliance for Caregiving and AARP. (2020).

Alzheimer's Association

<https://www.caregiver.org/caregiver-statistics-demographics>

Total Unpaid caregiver services estimated value of over \$500 billion per year.

4X what Medicare paid home care (\$121B) in 2020.

AARP Public Policy Institute. (2015). Valuing the Invaluable: 2015 Updated.

Medicaid budget in 2021: \$734 B

1 million people living with Parkinson's disease in US

90,000 diagnosed every year

Expected to double by 2040

Parkinson's is under-diagnosed

Who are the caregivers?

60% of unpaid caregivers are women.

Average age 49 (spans all age groups)

Provide care 20 hours/week

Most likely a spouse or daughter of care recipient

75% of care recipients are 65 or older

40% live with the recipient

25% caring for more than one person

60% work at least part time

1/3 have at least one significant disability *themselves*

“Learn as you go” – nearly all have no formal caregiving training.

AARP National Alliance for Caregiving, May 14, 2020

Out of pocket expenses for families who use paid caregivers averages about \$50K/year.

DHHS Office for Assistant Secretary for Planning and Evaluation

June 2015

Caregiver burden

Time – direct care, financial decision-making, transportation, appointments, shopping etc.

Personal development – life is “on-hold”. Feel out of sync with peers. Unprepared for tasks of caregiving.

Physical – fatigue, neglecting personal health needs - 25% report their health has worsened.

JAGS Vol. 55, No. 9 September 2007 Predicting Caregiver Burden from Daily Functional Abilities of Patients with Mild Dementia. AARP Nat. Alliance Caregiving 2020

Social – family conflicts, isolation, damaged relationships – including marital relationships, loneliness.

Stress/anxiety – worry, negative feelings toward care receiver, resentment, anger, guilt, *depression*

May Shorten lifespan

Worse health outcomes - with increases in:

Hypertension

Diabetes

Chronic inflammatory illnesses

Cancer

Depression and anxiety

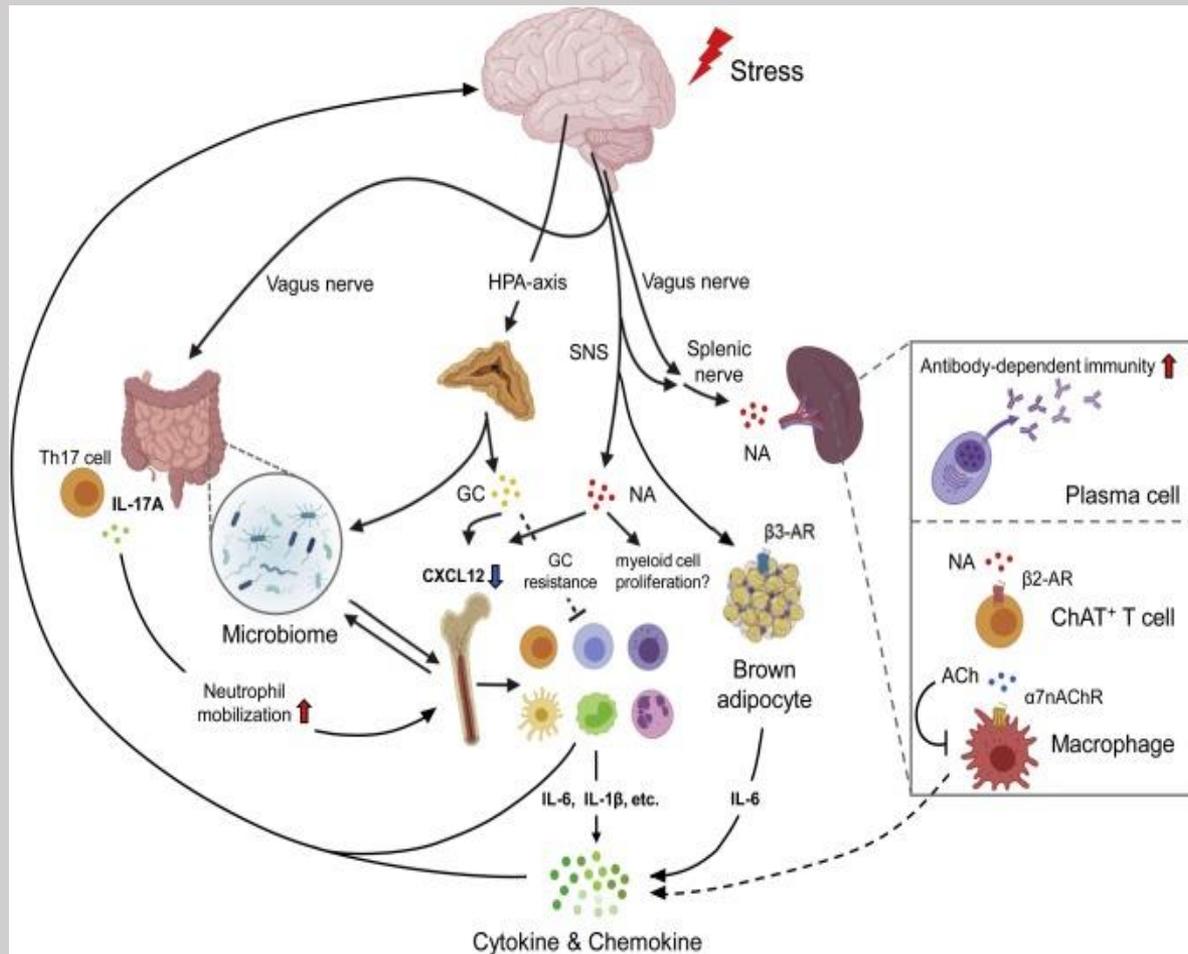
Obesity

Hospitalizations and ED visits

<https://www.bcbs.com/the-health-of-america/topics/caregivers>

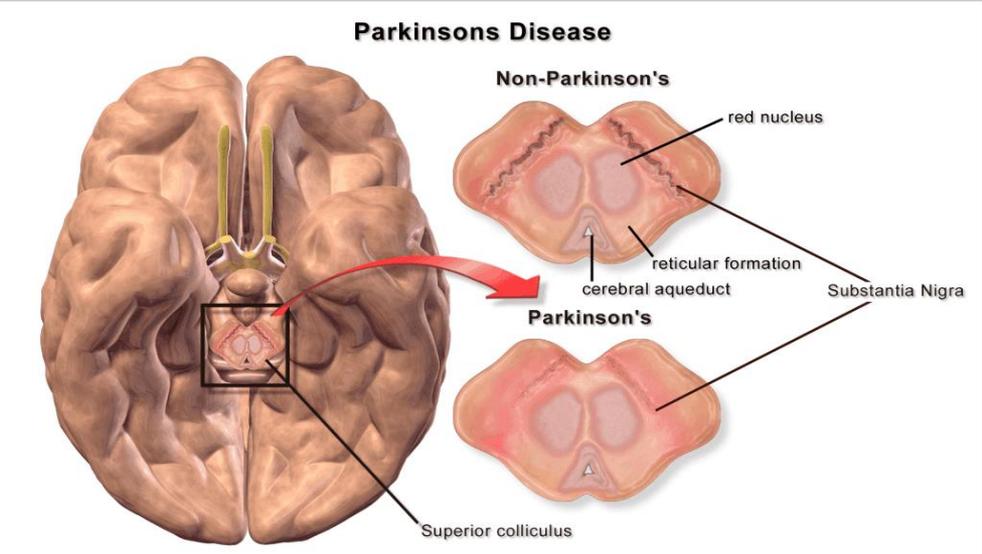
The Stress System



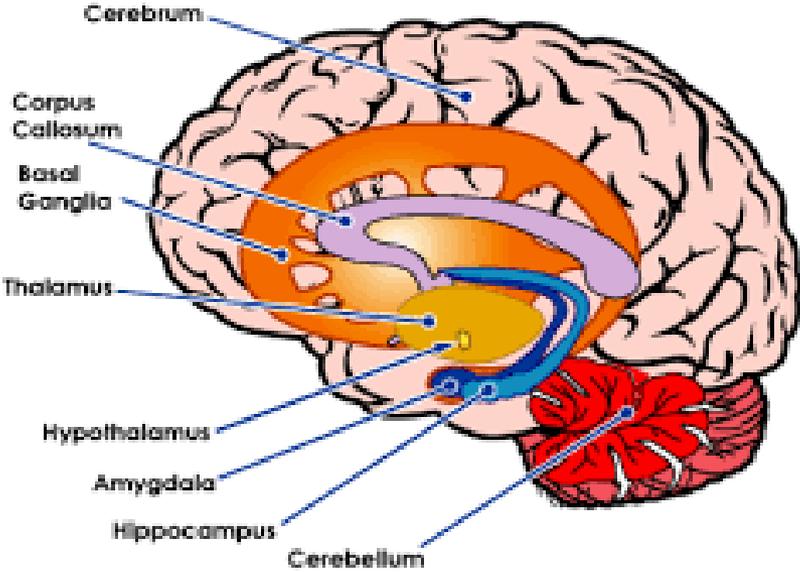


Stress and telomere shortening: Insights from cellular mechanisms

Ageing Research Reviews March 14, 2022

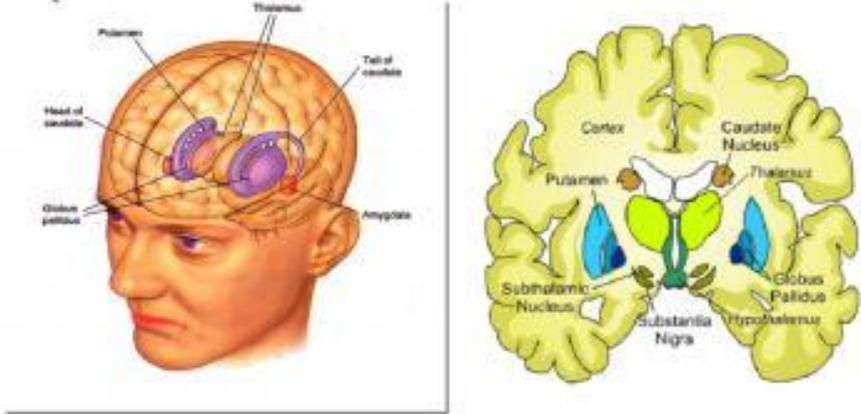


Basal Ganglia and Limbic System

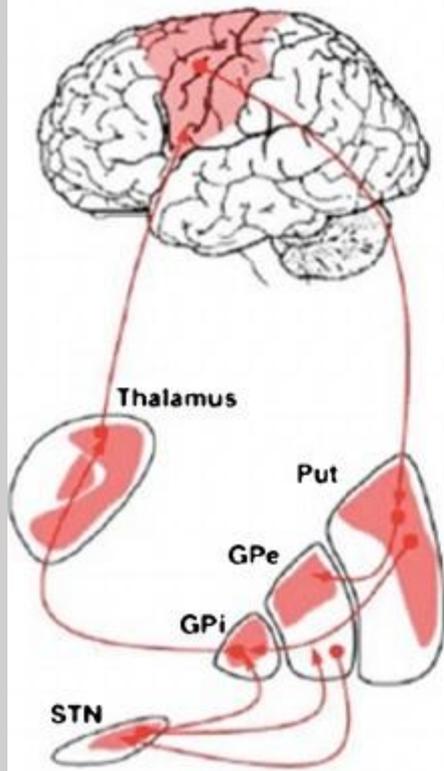


©2005 HowStuffWorks

Basal Ganglia

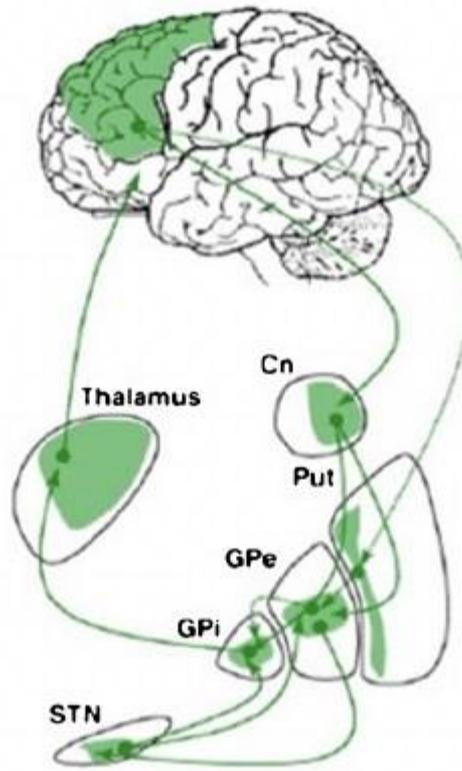


Sensorimotor and premotor cortex



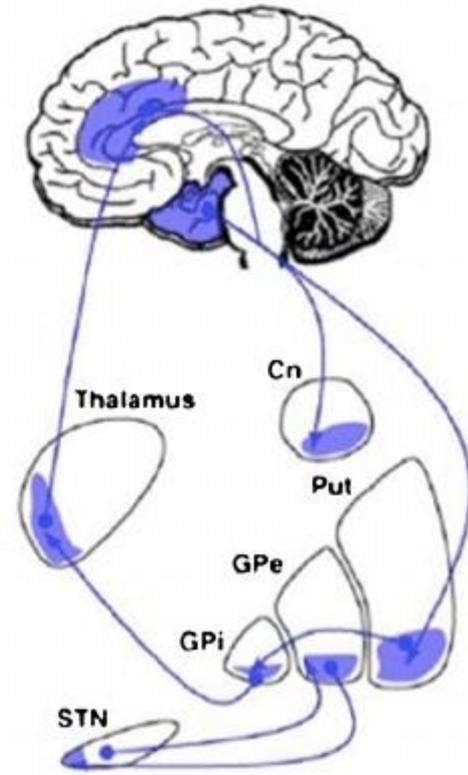
(a) Motor circuit

Dorsolateral prefrontal and lateral orbitofrontal cortex



(b) Associative circuit

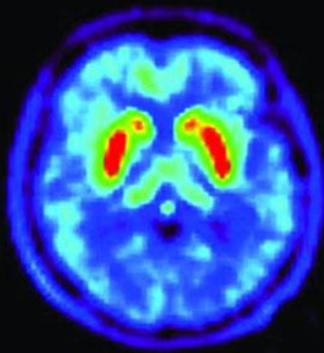
Limbic and paralimbic cortex, hippocampus and amygdala



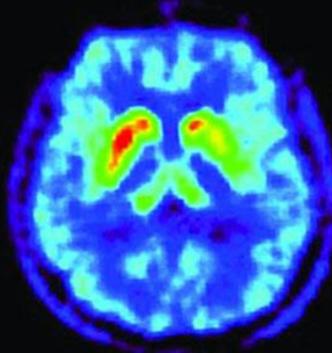
(c) Limbic circuit

Receptors	Location	Type	Mechanism	Function
D1	Olfactory bulb Nucleus accumbens Striatum Amygdala Hippocampus Frontal cortex Substantia nigra Hypothalamus	Gs-coupled	Enhanced intracellular cAMP through activated adenylate cyclase	Attention Learning Locomotion Sleep Impulse control Regulation of renal function Memory
D5	Hypothalamus Substantia nigra Cortex	Gs-coupled	Adenylate cyclase	Motor Learning Cognition Decision Making Renin Secretion
D2	VTA Olfactory bulb Striatum Cerebral cortex	Gi-coupled	Increased level of cAMP intracellular by activating adenylate cyclase	Reproductive behavior Locomotion Sleep Attention
D3	Cortex Islands of Calleja Striatum	Gi-coupled		Locomotion Regulation of food intake Impulse control Cognition
D4	Hypothalamus Amygdala Frontal cortex Nucleus accumbens	1- Gi-coupled		Attention Impulse control Reproductive behavior

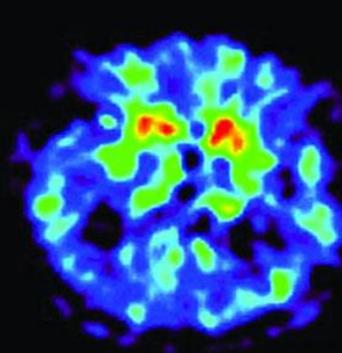
[¹⁸F]-Dopa Uptake



Healthy Control



Early Parkinson's

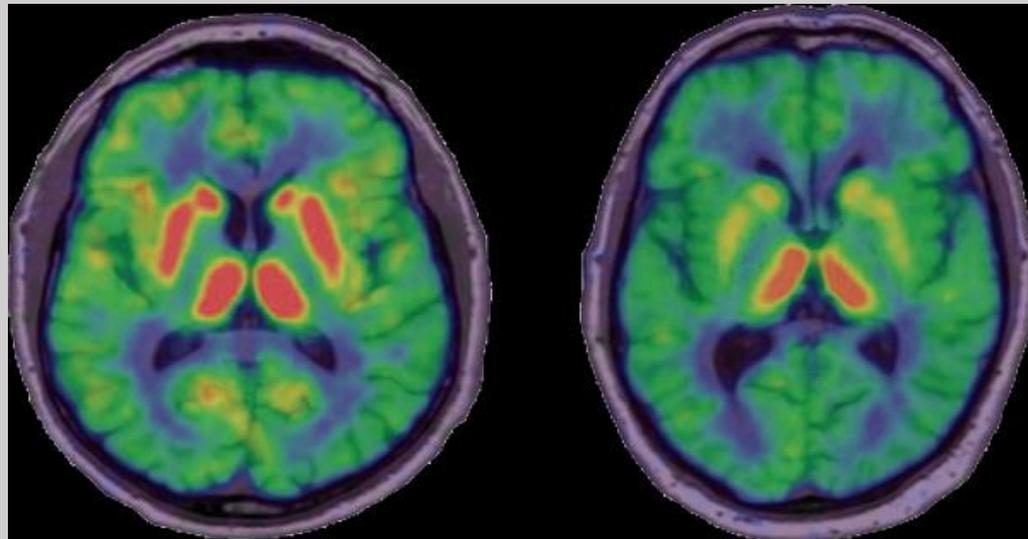


Advanced Parkinson's

1.6



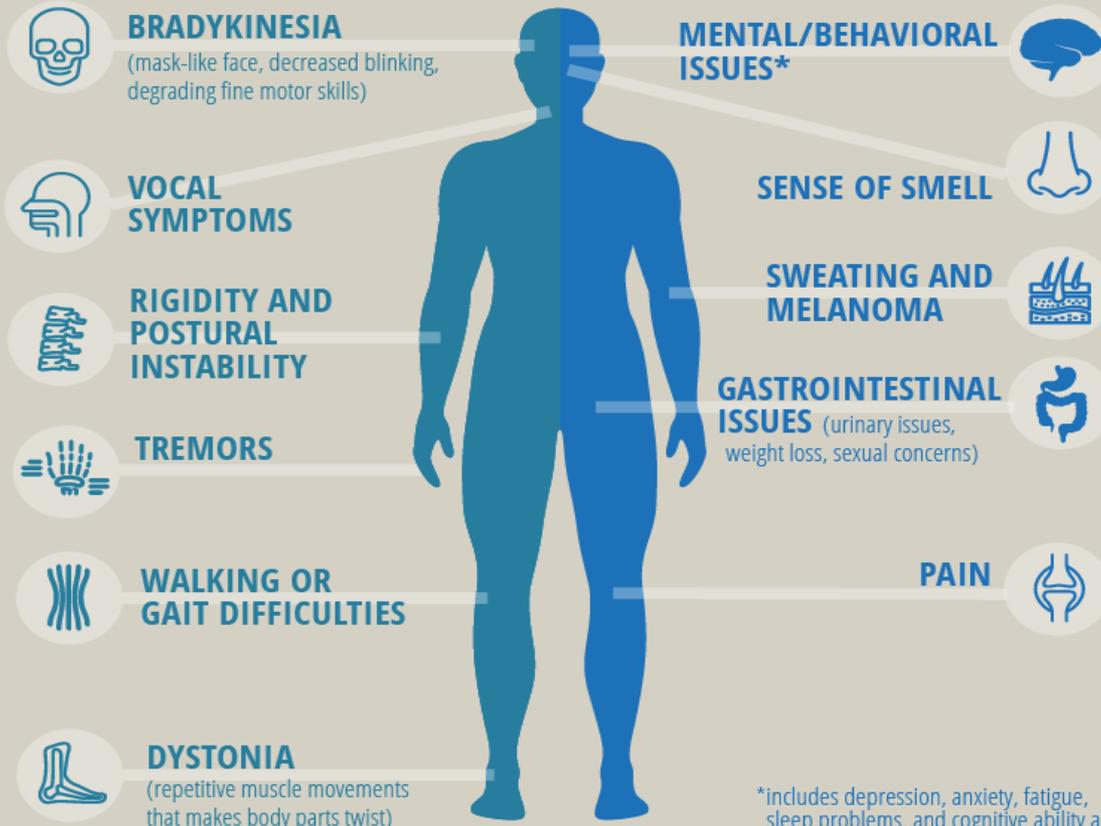
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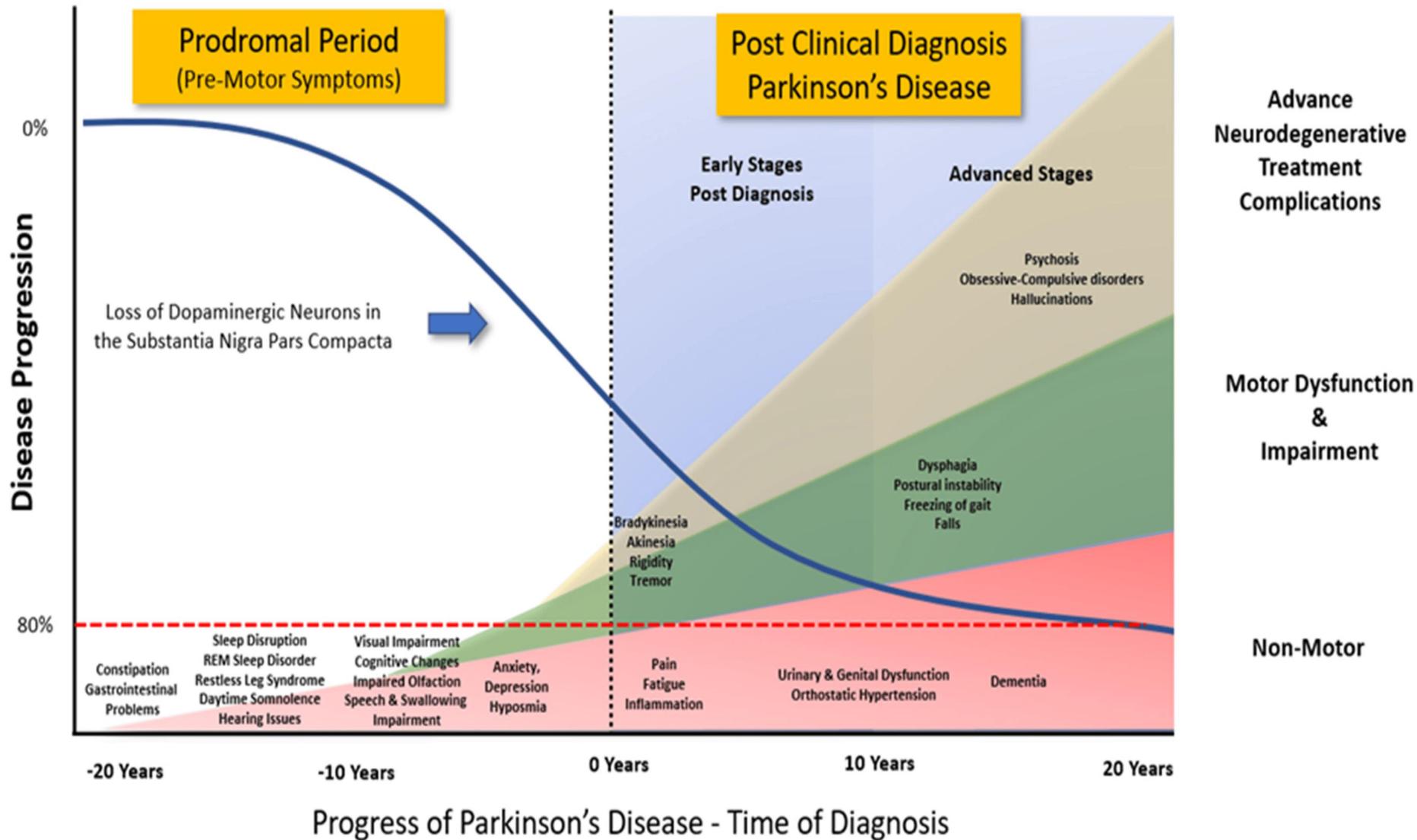
PARKINSON'S DISEASE

Motor Skill Symptoms

Nonmotor Skill Symptoms



*includes depression, anxiety, fatigue, sleep problems, and cognitive ability and personality changes



HOEHN AND YAHR SCALE

STAGE 1

Only one side of the body is affected

STAGE 2

Symptoms affect both sides of the body

STAGE 3

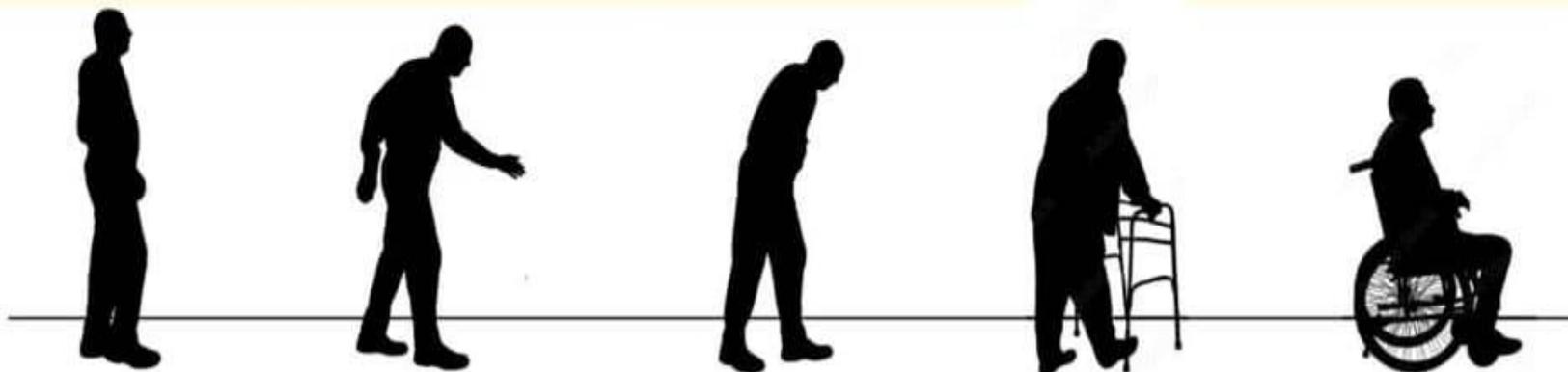
Balance and stability become affected

STAGE 4

Symptoms increase, however are able to stand and walk

STAGE 5

Assistance is required for everyday activities



Caregiver burden in PD

Early – adapting to new situation and worry about future

- lack of a well-defined plan
- lack of training and education about PD

Later- motor and *non-motor* symptoms add to burden/stress:

Depression/anxiety

Apathy

Cognitive impairment/dementia

Impulse control/psychosis (hallucinations)

Sleep issues

Pain

Positives from Caregiving:

Sense of Accomplishment – learning new skills, being resourceful, developing a support network

Being present at a time that could be very lonely and fearful for the loved one.

Personal/lasting change – perspective on life, relationships and general outlook

Making a Difference – in someone's life every day.

Memories of the loved one

Integrating the meaning of caregiving through self-awareness, adaptive/coping interventions, and personal growth can buffer the negative effects of stress on telomeres.

Stress resilience: Narrative identity may buffer the longitudinal effect of chronic caregiving stress on mental health and telomere shortening

AE Mason et al. Brain Behavior and Immunity Mar 2019

What works:

Multicomponent interventions had positive effects on caregiver burden, well-being, and ability/knowledge - were variable on depression.

Psychoeducation

Skills/knowledge training

Professional or peer support

Case management

Exercise

Meditation/mindfulness

What works:

Respite/daycare interventions were effective on:

Relieving caregiver burden

Depression

Well-being

How Effective Are Interventions With Caregivers? An Updated Meta-Analysis

S. Sörensen et al. *The Gerontologist*, Volume 42, Issue 3, 1 June 2002

Effectiveness of Multi-Component Interventions on the Positive and Negative Aspects of Well-Being among Informal Caregivers

Jinjie He et al *Int J Environ Res Public Health* Jun 2022

What works:

Training care *recipients* was effective in increasing caregivers' subjective well-being and reducing care receivers' symptoms.

One-on-one worked better than groups.

Groups more effective with regard to improving **care receiver** symptoms.

How Effective Are Interventions With Caregivers? An Updated Meta-Analysis

S. Sörensen et al. *The Gerontologist*, Volume 42, Issue 3, 1 June 2002, Pages 356–372,

Recommendations for changes to the “health system”:

- *Formally recognize and identify caregivers*, incorporate them into care plans, discharge planning and document this in health records
- *Assess the needs of families* who provide informal care - including hours spent, caregiving intensity, and strain.
- *Coordinate care through navigators*, case managers, and advocates. Particular attention to transportation, support groups, skills training, and respite care.

Include “caregiving” into health professions’ educational curricula. Prepare clinicians to meet and communicate effectively with multiple family members.

-Develop partnerships with community programs and organizations that support caregivers – use an integrated public health approach

Recommendations to Improve Health Outcomes Through Recognizing and Supporting Caregivers LK Leykum et al. J of Gen Internal Med
volume 37, pages1265–1269 (April 2022)

Progression (four arbitrary stages):

1. Diagnosis – recognition of symptoms/disease
2. Maintenance – relative stability – medications and movement
3. Increasing complexity – worsening motor and non-motor symptoms. Motor instability. Frequent medication changes.
4. Palliative – unresponsive or intolerance to dopaminergic medications, feeding issues, increasing complications and life-threatening comorbidities

Hospice – a Medicare benefit that you have earned and is your right.

Designed to be a six-month benefit – may be longer

Hospice services/hospice team:

Nurse, doctor, social worker, chaplain, personal aides, bereavement coordinator, volunteers

Durable medical equipment

Medications related to hospice diagnosis and comfort care

Parkinson's Hospice Eligibility:

One or more of the following:

Rapid disease progression - now **wheel chair or bedbound**

Speech progression to **barely intelligible or unintelligible**

Requires **pureed diet**

Swallowing difficulties or aspiration – feeding tube has been recommended

Recurrent pneumonia or other infections

Weight loss – **BMI of 18 or less**

Difficultly with activities of daily living such as feeding, bathing, etc.

When dopaminergic **medications are no longer helping** and side effects outweigh benefit.

Artificial feeding

Over 200,000 placed in US each year.

Placed to prevent aspiration, consequences of malnutrition, improve pressure ulcers, functional status and patient comfort.

Management of Feeding Tube Complications in the Long-Term Care Resident
Annals of Long-term Care: Apr 01 2008

Alternatives to feeding tubes

- avoid sedating/drying medications/anticholinergics
(interfere with swallowing)
- liberalize the diet - give foods the patient likes
- hand feed patients*
- position carefully while feeding

Little or no evidence that artificial feeding improves these clinical outcomes and *significant evidence that harm can result.*

Tube Feeding in Patients With Advanced Dementia JAMA October 1999 vol. 282, No. 14)

<http://jama.ama-assn.org/cgi/content/full/282/14/1365>

AGS Position Statement

www.americangeriatrics.org/products/positionpapers/feeding_tube_placement.pdf

Green Valley



We Nurture Human Connection

Member - Neighbors Care Alliance - A partnership with Pima Council on Aging

Feeling lonely?

...or stressed?

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520 440-4457

GVCares@outlook.com

Parkinson's Foundation

<https://www.parkinson.org/resources-support/carepartners/resources>

MJF Foundation

<https://www.michaeljfox.org/news/care-partners>

Parkinson's Support Group of Green Valley

(520) 499-3858

<http://www.gvparkinsons.org>

Pima Council on Aging (PCOA)

www.pcoa.org

520.790-7262