WELCOME TO EXPERT BRIEFINGS

Understanding Pain in Parkinson's

- The program will begin at the hour.
- Participants will be muted and off video.

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Welcome

James Beck, PhD

Chief Scientific Officer, Parkinson's Foundation

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Our Mission

The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience and passion of our global Parkinson's community.

We have everything you need to live better with Parkinson's.

Poll: Getting to Know You

What best describes your connection to Parkinson's disease?

- Person with PD
- Spouse/Partner
- Parent has/had PD
- Other family
- Healthcare Professional
- Physician/Clinician
- Scientist/Researcher
- Nurse/Nurse Practitioner
- Other

Meet Your Expert

Apurva Zawar, PT, DPT

- Board Certified Geriatric Clinical Specialist
- Volunteer Assistant Clinical Professor at University of California, San Francisco
- Founder of Beyond Rehab

Expert Briefings
Parkinson's Foundation

Understanding Pain in Parkinson's

Dr. Apurva Zawar, PT, DPT, GCS
Board Certified Geriatric Clinical Specialist
Founder, Beyond Rehab
Volunteer Assistant Clinical Professor, UCSF

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Disclosures

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This presentation, based on my professional experience, current research, and best practices, aims to provide general information about pain in Parkinson's disease.

It's important to remember that each individual's experience with Parkinson's disease and pain is unique, and the strategies and treatments that work best can vary. Therefore, this presentation is not intended to replace individual medical advice. Always consult with your healthcare provider before making any changes to your treatment plan.

While every effort has been made to ensure the accuracy of the information presented, BeyondRehab and Parkinson Foundation cannot be held responsible for any errors or omissions. We accept no liability for any loss or damage you may incur. Always seek medical advice from a qualified healthcare provider for diagnosis, treatment, and answers to your medical questions.

Learning objectives

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- ❑ Understand the pain presentation and causes of pain in Parkinson's disease and how it may change over time.
- ❑ Acknowledge the impact that pain has on mental health and quality of life.
- ❑ Learn about the different pharmacologic and non-pharmacologic treatments for pain.

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Parkinson's Disease

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- PD involves wide range of motor and non-motor presentation.
- It's important to have whole person centric and multimodal care to manage it.

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Prevalence of Pain in PD

- As compared to general population, Parkinson's patients have been confirmed to present with a **significantly higher level and prevalence of pain.**
- In Parkinson disease, chronic pain is present in 20% of patients at the time of diagnosis associated with the early motor stage but can affect **up to 80%** of the patients during disease. (Mylius et al. 2021)
- Pain significantly diminishes QOL in someone with PD. (Choi et al.2017)

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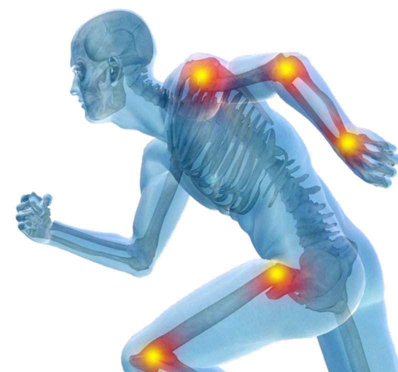
Prevalence of Pain in PD

~80%

- Important non-motor PD symptom
- Can be experienced across all clinical stages

Source: Mylius et al. 2021



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Pain in PD Presentation

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Pre-motor	Early PD	Advanced PD
▪ Pain symptoms can **appear 1 - 2 years before** the onset of motor feature. ▪ Shoulder-arm-syndrome, is a very typical early presentation. ▪ 5% of PD patients reported pain as their first symptom.	▪ Pain is related as one of the **most troublesome non-motor symptom.** ▪ It affect the side of the body that was initially impacted by motor symptom. ▪ Chronic pain is present in 20% of patients at the time of diagnosis.	▪ Pain is **more common** in advanced PD stages. ▪ Patients that had PD for more than 5 years reported a **35% higher incidence of pain** compared to those with early-stage disease.

Causes of Pain in PD

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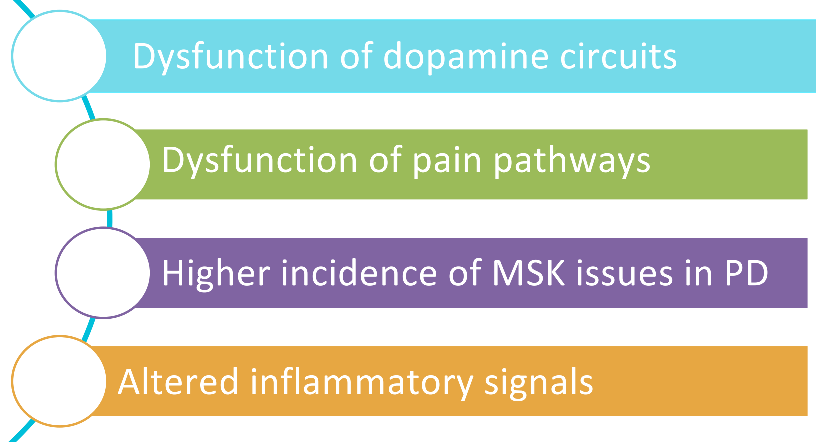
Pain in PD is **complex** and often **multifactorial** & can occur at any time during the disease course.

PRIMARY CAUSES



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Discovering Pain in PD

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Is pain felt differently in PD?

- **Yes**, pain is felt differently.
- **Lowered threshold** for pain perception.
- **Altered** pain sensation.

Impact of Pain on Quality of Life

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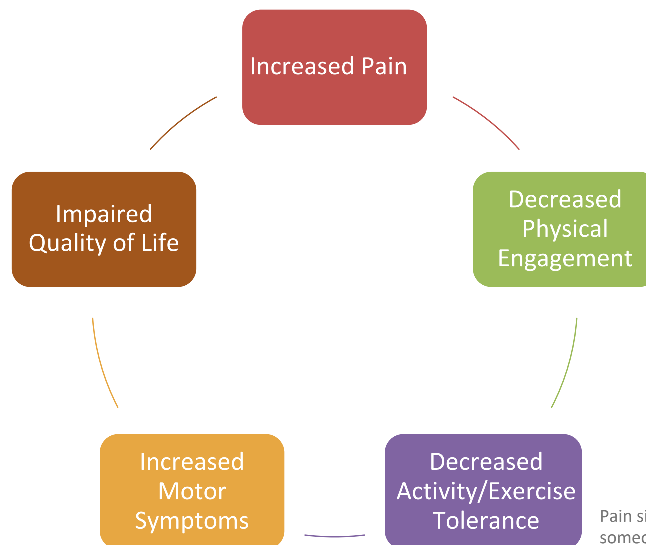

Pain significantly diminishes QOL in someone with PD. (Choi et al.2017)

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Impact of Pain on Quality of Life

- **Mental Health Toll:** Chronic pain in Parkinson's amplifies stress, anxiety, and depression, deeply affecting mental well-being.
- **Decline in Quality of Life:** Neglected pain diminishes life satisfaction, hindering participation in daily activities and social interactions.
- **Reduced Exercise Engagement**: Pain discourages involvement in vital exercise programs crucial for managing motor symptoms.
- **The Cycle of Decline**: Decreased exercise due to pain worsens motor symptoms, perpetuating discomfort and lowering overall quality of life.

Pain significantly diminishes QOL in someone with PD. (Choi et al.2017)

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Breaking the Vicious Pain Cycle and Controlling Pain

Recognizing the pain pattern

Differentiating pain from non-PD specific pain

Effectively tracking and communicating with the providers

Integrative care management combining Self management and multimodal care

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What Does Pain Mean to You?

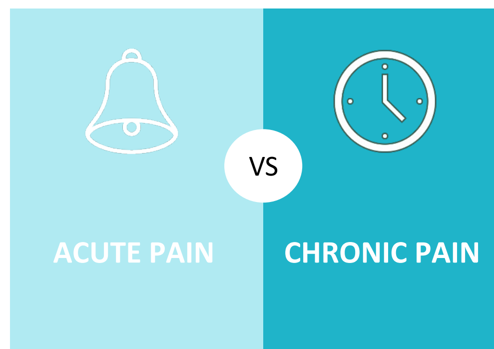
Revised IASP Definition of Pain (2020)

"An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage."

The Pain Management Guide

Recognize Pain: Acute vs Chronic

A signal of discomfort in the body



Pain that lasts for a long time (>3months)

Categorize Pain

PD Related Pain

PD Unrelated Pain

PD-Pain Classification System (PD-PCS)

Source: Mylius V, Perez Lloret S, Cury RG, et al. The Parkinson disease pain classification system: results from an international mechanism-based classification approach. Pain. 2021;162(4):1201-1210.

Step 1: PD - Pain Classification System

- Has your pain started or become more **severe** since the onset of PD symptoms?
- Does your pain worsen when rigidity, tremors, or slowness of **movements are more intense**?
- Is your **pain associated** with excessive or abnormal **movements** (choreatic dyskinesia)?
- Does your **pain improve** when taking PD **medications**?

Step 1: PD - Pain Classification System

If you answered **Yes** to any of the questions in the previous slide, then pain is considered as **PD related pain**.

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Step 2: PD - Pain Classification System

PD related pain can be categorized in 3 subgroups:

A. Nociceptive Pain (Musculoskeletal and Dystonic Pain)

B. Neuropathic Pain (Radicular Pain)

C. Nociplastic Pain (Central Pain)

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Nociceptive Pain

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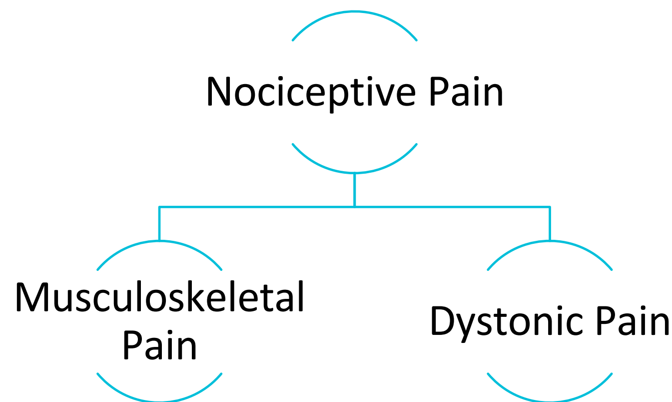
Nociceptive pain arises from actual or threatened damage to non-neural tissue due to activation of nociceptors.



Nociceptive pain

Parkinson's Foundation

Nociceptive pain arises from **actual or threatened damage** to non-neural tissue due to activation of nociceptors.

It includes most of the musculoskeletal pain syndromes:

- **Truncal deformities:** Kyphoscoliosis, camptocormia, Pisa syndrome and dropped head syndrome
- **Joint disorder:** Frozen shoulder, dystonic joints and joint pain related to osteoarthritis and other inflammatory conditions

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Nociceptive pain

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- These comprises of **musculoskeletal pains** due to motor status fluctuations such as off-period pain, painful dystonic spasms, as well as peak of dose pains.
- **Painful dystonia** develops in individual receiving long term **levodopa treatments**. It may occur in the morning, before the first dose of levodopa or even during medicated periods.

Neuropathic Pain (Radicular)

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- Neuropathic pain is associated with lesion or **disease of the peripheral or central somatosensory system**.
- Neuropathic features of **pain include burning, electric shock-like, and pins-and-needles sensations**.
- It is presumably caused or **exacerbated by the postural changes** in PD.

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Nociplastic Pain (Central)

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- Nociplastic pain syndrome comprise instances where **nociceptive system is over-active** without any evidence of somatosensory lesion or peripheral activation of nociceptors due to actual or potential tissue damage.
- Central sensitization which is not specific to a single pain type and diffused across the body. It is described as **unexplainable, stabbing, burning sensation** often diffused across the body.
- **Leg motor restlessness, non-motor off, oro-facial and visceral pain** will be classified as nociplastic pain.

Step 3: Rate Your Pain Level

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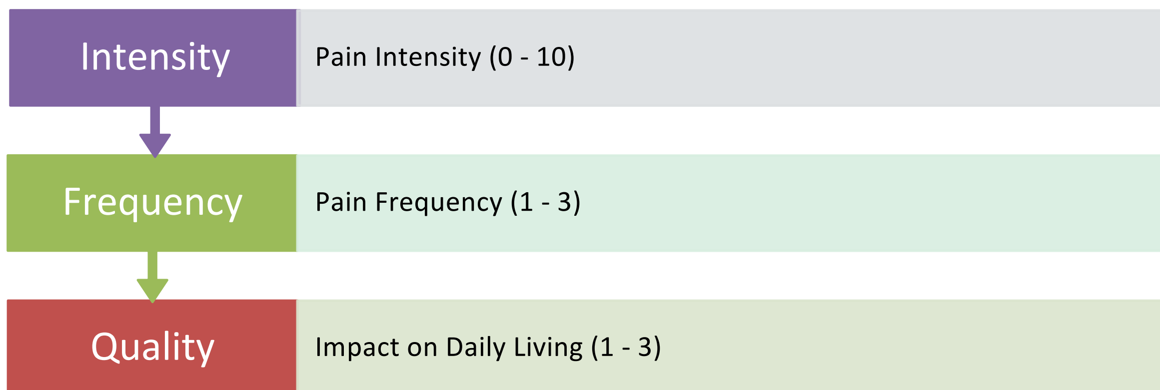

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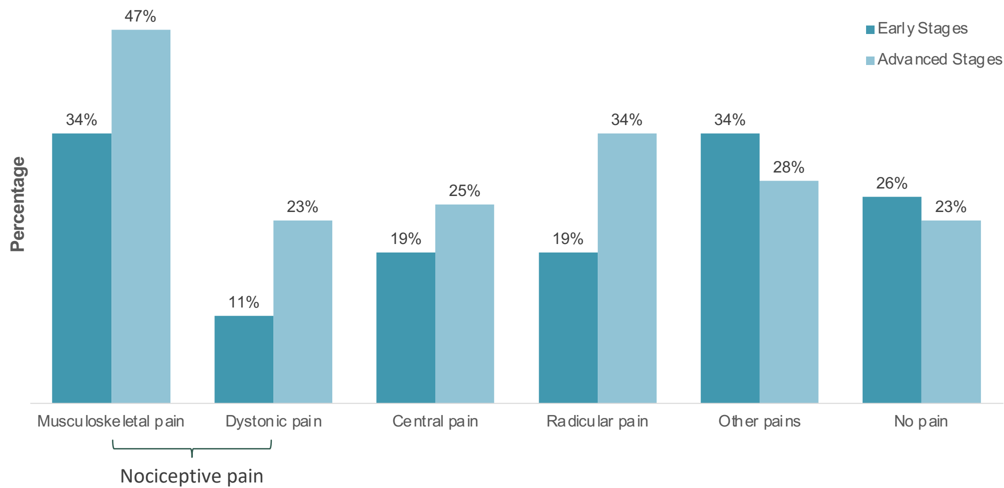
Incidence and Prevalence of Chronic Pain in Parkinson's Disease



Source: Pain in Parkinson´s disease: A cross-sectional study of its prevalence, types, and relationship to depression and quality of life

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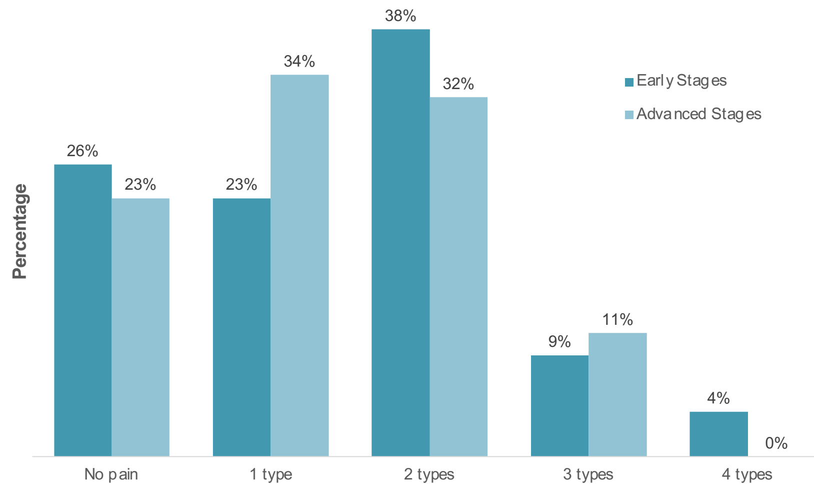
Pain in PD Statistics



Source: Pain in Parkinson´s disease: A cross-sectional study of its prevalence, types, and relationship to depression and quality of life

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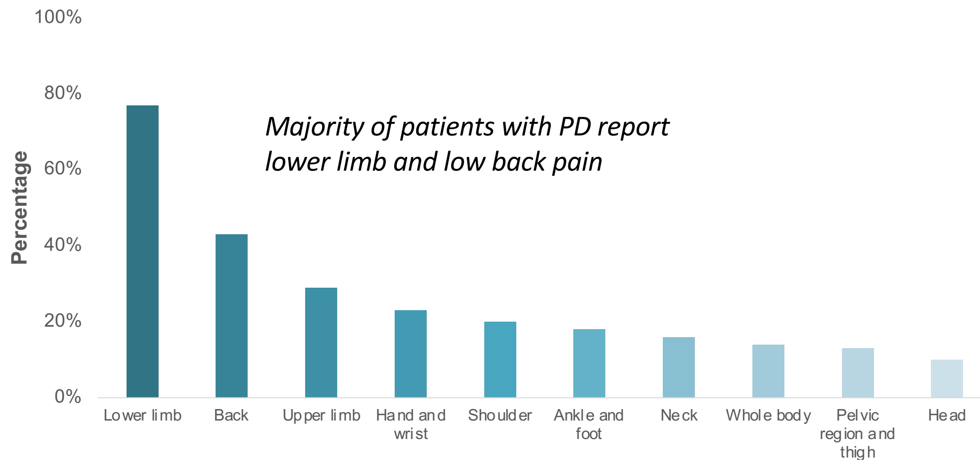
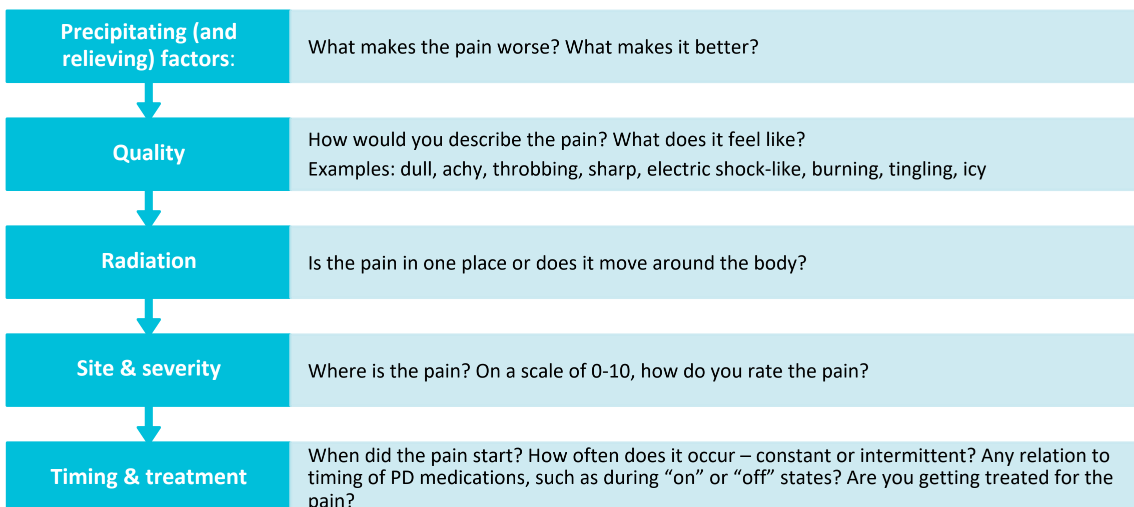
Musculoskeletal Pain



Source: Li J, Zhu BF, Gu ZQ, et al. Musculoskeletal Pain in Parkinson's Disease. Front Neurol. 2022;12:756538. Published 2022 Jan 21. doi:10.3389/fneur.2021.756538

Pain Assessment And Tracking



Pain Assessment and Tracking

Date	Precipitating Relieving factors	Quality Describe the pain	Radiation Does the pain move around?	Site and Severity Rate the pain (0-10)	Timing and treatment Relation to timing of PD medications

Building Your Team

Key point of contact is your Movement Disorder Specialist

Optimization of antiparkinsonian treatment should always be the fundamental of treatment

Source: C. Buhmann et al.

Your Team and Resources

- Movement disorder Specialist
- Neuro Physical Therapist
- Occupational Therapist
- Speech Therapist
- Primary Care Physician
- Psychologist
- Wellness PD coach

Integrative Care Management

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- Integrated Care (IC) is a person-centered approach aimed at delivering comprehensive and coordinated care.
- It involves a multi- or interdisciplinary team working across various settings and levels of care.
- Individuals with chronic conditions are actively involved in their own care, as they are essential partners in managing their diseases.

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Management: Pain in PD

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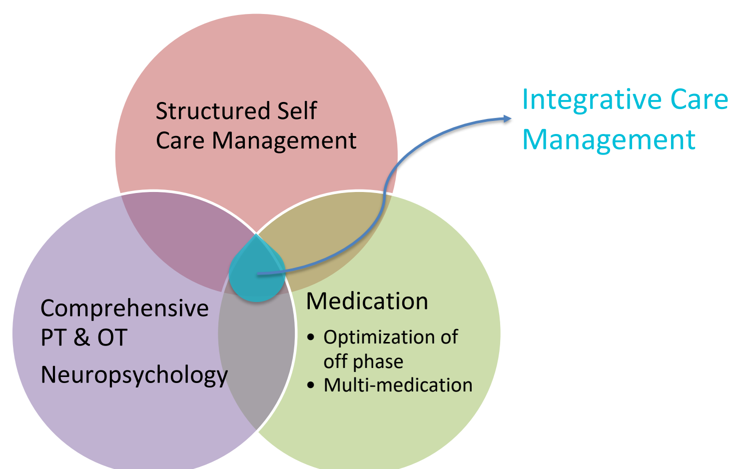

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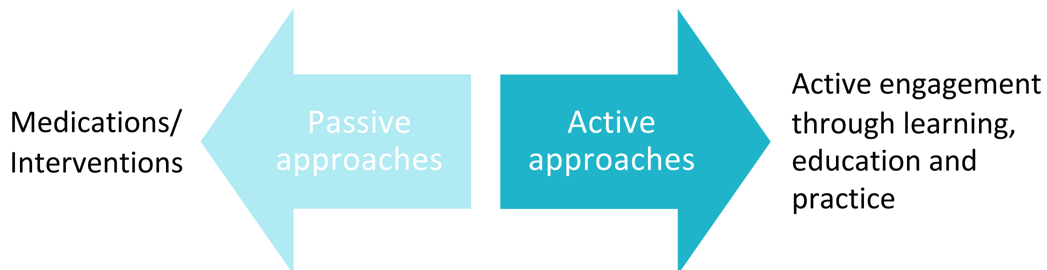
Integrative Care Management

Medications/ Interventions



Active engagement through learning, education and practice

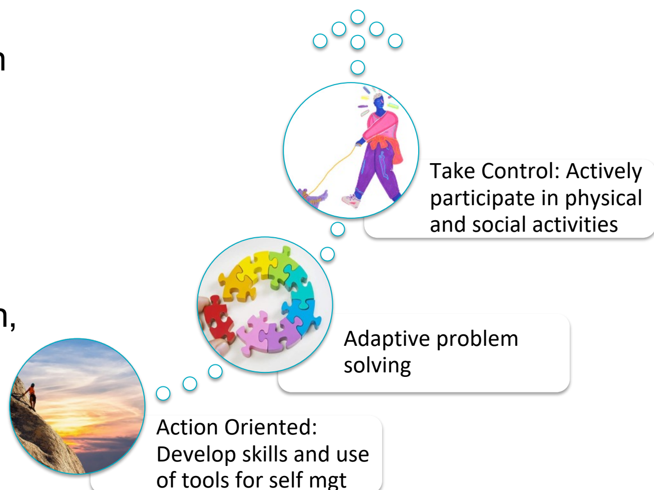
Researches have shown that **Active interventions**, which require a person's effort, are more effective than passive interventions.

Source: American Chronic Pain Association Guide 2021

Integrative Care Management

The primary goals of using non-pharmacological approaches for pain management are:

- To empower individuals with the tools and skills necessary for self-managing their pain.
- To reducing reliance on medication, and
- To actively participate in physical and social activities.



Self Management Program

Self-management includes the systematic application of education and supportive interventions by health care professionals to increase skills and confidence in managing health problems.

Goals:

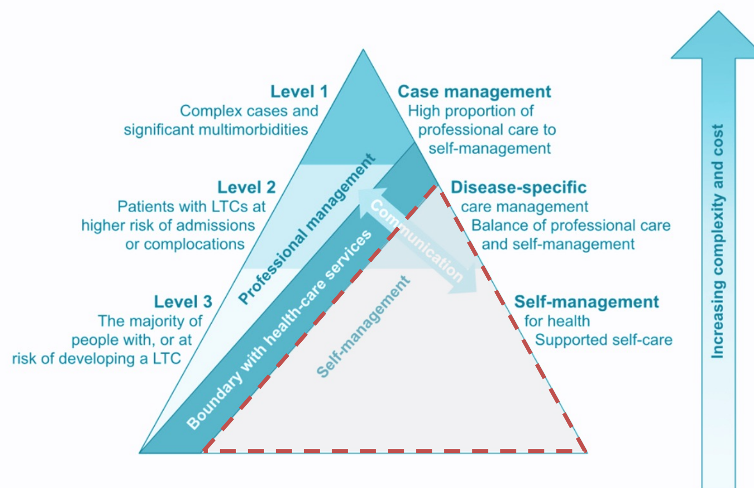
Help you become the expert on managing your pain

Give you a "toolbox" of skills, techniques, healthy habits and exercise that will help you stay active and return to previous activities

Help you become fitter and healthier despite your pain

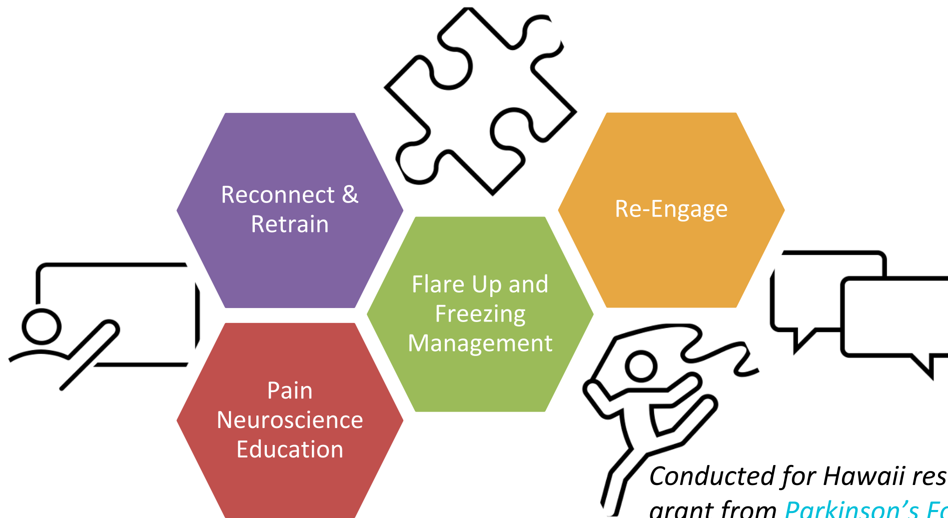
Help alleviate fears or concerns you have about pain provoked by activity

Self Management Program



Source: "Kaiser pyramid" about the interaction between patient disease-related self-management and professional management

Case Study
PD Powerup: A Pain Management Program



Conducted for Hawaii residents with a generous grant from Parkinson's Foundation

Goals of PD Powerup Program

To empower pain understanding

Learn to effectively interpret the pain, factors influencing the pain experience, increase confidence and autonomy in managing pain.

Active coping skills

Shift of health and well-being responsibility from the health care professionals and therapists to the person.

Re-engage in life activities

Decrease fear, increase movement and engagement.

Outcomes of PD Powerup Program

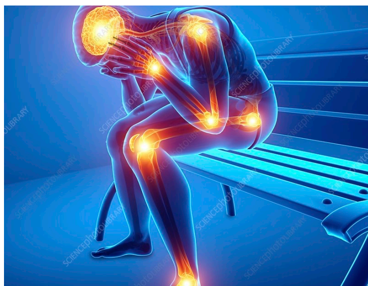
Decreased dependency on over-the-counter pain medications by **20%.**

Increased use of active coping strategies by **30%.**

Improved confidence and engagement in physical activities.

The program was effective in a group setting as it allows for sharing of experiences and learning from peers, fostering camaraderie and support.

Recovery is Possible!!



Re-connecting → Re-training → Re-engaging

Next: Where do you begin?

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Creating the game plan

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- Initiate tracking and maintaining pain log diary.
- Communicate and discuss your pain presentation with your MDS, PT and other team members.
- Collaborate closely with your healthcare team for effective management of your symptoms.
- Enhance self-management abilities, fostering greater confidence in managing your condition.

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Key Takeaways

- Effectively track, assess and communicate with your providers.
- Combination of therapies and interventions needed may differ.
- Living a full life with pain requires that the person take an active role in the recovery process.
- Success is achieved when a person has learned to self-manage their condition.

Thank You!

Dr. Apurva Zawar, DPT, GCS

Founder, BeyondRehab

Connect me at:

www.beyondrehab.health

info@beyondrehab.health

Download Chronic Pain Workbook

www.beyondrehab.health/workbook

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2024 Expert Briefings

Wednesday, March 13
Understanding Pain in Parkinson's

Wednesday, April 10
Research Update: Working to Halt PD

Wednesday, May 8
Trouble with Zzz's: Sleep Challenges with Parkinson's

Wednesday, September 11
Solving the Challenge of Apathy in Parkinson's

Wednesday, October 9
More Than PD: Managing Multiple Chronic Conditions

Wednesday, November 13
What's On Your Mind? Thinking and Memory Changes in Parkinson's

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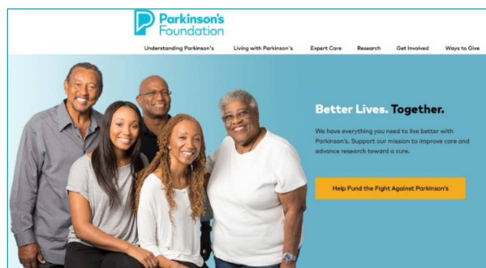

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Before You Go…

Your feedback is important to us!
Please complete the evaluation after the close of this webinar.

EXPERT BRIEFING EVALUATION

Page 1 of 1

1. What best describes your connection to Parkinson's disease (PD)?

- ☐ Person with Parkinson's
- ☐ Spouse / Partner
- ☐ Parent has / had Parkinson's
- ☐ Other family of person with Parkinson's
- ☐ Friend of person with Parkinson's
- ☐ Healthcare Professional
- ☐ Other