

PARKINSON'S AND IT'S PSYCHOSOCIAL IMPACT ON PATIENT'S AND FAMILIES

Lower East Side Inter-Agency Council 2018

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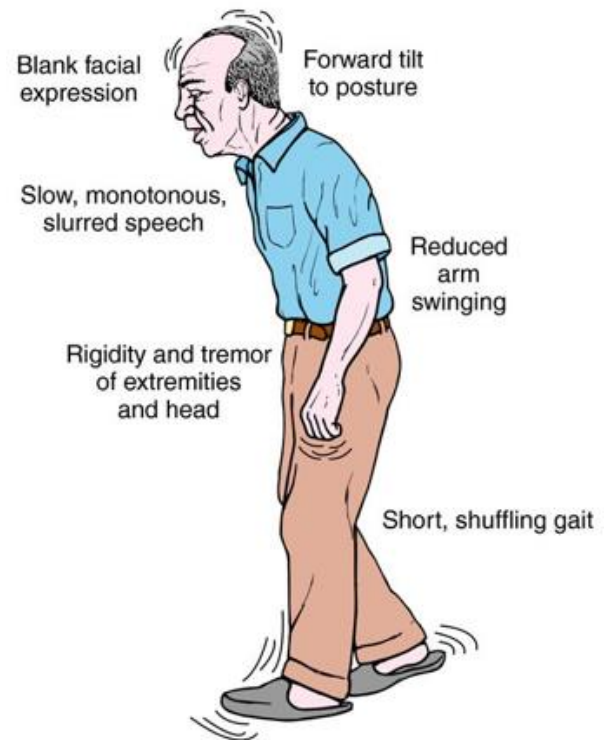


Fresco Institute for Parkinson's and Movement Disorders at NYU Langone Medical Center

- Mission: to advance treatment, education, and research for Parkinson's and other movement disorders
- National Parkinson Foundation/ Parkinson's Foundation Center of Excellence since 2009
- Services include:
 - Movement Disorders Clinic
 - Clinical Research
 - Social Work and Supportive Services Program

What is Parkinson's Disease?

- Parkinson's disease is a progressive neurodegenerative disorder that affects dopamine-producing neurons in a specific area of the brain called the substantia nigra
- Cardinal Symptoms of Parkinson's Disease
 - Tremor
 - Bradykinesia (slowness of movement)
 - Rigidity (stiffness)
 - Gait and balance problems



Parkinson's Statistics

- Nearly one million Americans and 10 million people worldwide live with Parkinson's Disease
- Approximately 60,000 people in the US are diagnosed with Parkinson's disease each year
- As the population ages, the number of individuals diagnosed with PD will continue to increase
- Average age at diagnosis: 62
- Men are one and a half times more likely to have Parkinson's than women

Other Signs and Symptoms

- Facial masking
- Hypophonia
- Micrographia



Non-Motor Parkinson's Symptoms

- Depression
- Anxiety
- Apathy

Parkinson's Emotional Impact

- Anger
- Denial
- Disbelief
- Embarrassment
- Fear
- Grief
- Stress
- Worry
- Guilt
- Helplessness
- Hopelessness
- Humiliation
- Isolation
- Loss
- Overwhelm
- Sadness
- Shame
- Stigma

Common Concerns

- Reported by patient and/or care partner:
 - ☐ Communication changes
 - Loss of facial expression
 - Changes to voice volume, animation, and clarity
 - Handwriting changes
 - Changes in abilities on phone & computer
 - Change in initiation
 - Loss of confidence in ability to express effectively can lead to:
 - Not participating, not engaging, depression, isolation

Common Concerns

- Reported by patient and/or care partner:
 - Cognitive changes
 - Marital strain/caregiver stress and burnout
 - Family tension (between adult children, others)
 - Social isolation
 - An individual's world may become smaller and smaller

Care Partner and Family Strain

Care partners' range of needs are often overlooked at patient appointments

Medical providers often have varying levels of understanding of the needs of the family affected by PD

Care Partner and Family Strain

- Falling concerns
- Medication management
- Self and couple redefinition: partner/spouse → patient/caregiver
 - Sexual and intimacy changes
 - Change in patient's insight and judgement
 - Change in roles: *“She handled all the bills, now I am and I’m lost.”*
 - Change in power structure: less partnership, more dependence



Support and Resources Available

Building the Parkinson's Team(s)

- As Parkinson's progresses:
 - Successful adaptation is within reach
- Building multiple teams for support:
 - Medical team
 - Home team
 - Community team
- Keeping the patient (and his/her support system) at the center of the team(s)

Team Members

- Patient and loved ones
- Movement disorders specialist
- Social worker/psychotherapist
- Nurse/nurse practitioner
- Neuropsychiatrist/neuropsychologist
- Primary care physician
- Allied health therapists – physical, occupational, speech
- Home health aide(s)
- Dietician
- Geriatric care manager
- Elder care attorney
- Financial manager

Services and Resources provided at the Fresco Institute

- Short-term supportive counseling at the Fresco Institute
- Support Groups for patients and spouses
- Advance Care Planning (HCP, eMOLST)

Services and Resources provided at the Fresco Institute

- Connection to exercise and allied health program throughout NYC
- Connection to home visiting programs throughout NYC
- Resource Referrals:
 - Psychiatry
 - In-home referrals
 - Elder care attorneys
 - PT, OT, speech
 - Home safety assessments
 - Home health care agencies
 - Palliative care and hospice
 - Many more

Fresco Institute Support Groups

- Professionally-facilitated, psychosocial support groups led by the Social Work Team from NYU School of Medicine and NYU Silver School of Social Work
 - Groups for both people with Parkinson's and care partners, separately
- 10-week sessions, 3 times per year
- Goal: develop active coping and adaptation skills through enhanced communication, shared experience, and the development of a peer support network in a safe and welcoming place

Monthly Educational Seminars

- We offer monthly educational group seminars that provide holistic education and resources for people who have been diagnosed with Parkinson's disease and their caregivers. Skilled and experienced professional nurses facilitate the groups, which are open to the community.

Reliable Resources

American Parkinson Disease Association

www.apdaparkison.com

Michael J. Fox Foundation

www.michaeljfox.org

Parkinson Foundation (Helpline)

www.parkinson.org

Parkinson Alliance

www.parkinsonalliance.net

www.DBS4PD.org

Parkinson's Foundation: www.parkinson.org



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1-800-4PD-INFO

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Believe in BETTER

Support our mission to help every person diagnosed with Parkinson's live their best possible life now. Your gift will help us fund better research, better treatment and better lives.

GIVE NOW

We make life better for people with Parkinson's through expert care and research. Everything we do helps people actively enjoy life with their friends, families, children and grandchildren until there is a tomorrow without Parkinson's.

Citations

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