

Outline

1. Non-motor symptoms of PD
2. What are depression, anxiety & apathy
3. Causes of depression, anxiety & apathy
4. Impact on quality of life
5. Treatment of depression, anxiety & apathy

The Seven Stages of Grief for Chronic Disease

Denial	Pleading, Bargaining and Desperation	Anger	Anxiety and Depression	Loss of Self and Confusion	Re-evaluation of Life, Roles and Goals	Acceptance
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Responses to disease

- Engulfment – disease disrupts all domains of life
- Rejection – neglecting and avoiding disease
- Acceptance – part of identity, not overwhelmed
- Enrichment – positive changes, enables growth



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Identity

How the hell did I come to be like this? Because this isn't me.



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Identity crisis



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Shifting perspectives model of chronic illness

How much does my disease
define who I am?

Story of your life

Different trajectory



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Identity

Body stops working the way it used to
Don't look the same or act the same
Can't do the same things
Loss of self + suffering



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Identity

What is the most challenging loss to accept?

Feelings of isolation?



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Complexity of PD



Diagnosis, symptomatology, progression, debility, QoL, adjustment to disease, etc.

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Complexity

Fundamental problem
Life can be so complex you'd rather be dead
Things get beyond your control
Multiple catastrophes at the same time
Life gets too complicated
No way out

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Fluctuations



- Different abilities/challenges from day to day, hour to hour
- Difficult to make plans – “lets see how I feel”
- Medication wearing off – worse depression, anxiety, cognition, fatigue, irritability, pain, motor symptoms

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Fluctuations

- Different in various settings with various people
- Hard to have consistent expectations



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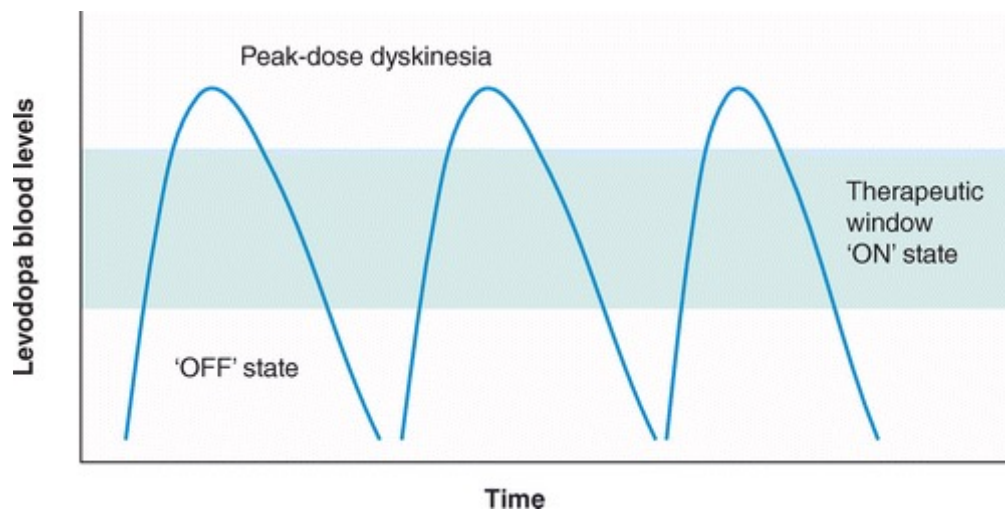
Impact on family

- “Is this John? Is this the Parkinson’s? Is he just not trying?”
- Manipulative? Malingering? Genuine? Authentic?
- Hard to know when to push and when to lay off
- Should I be mad at him? Can I not blame him?
- Disease? Personal responsibility?
- Outside of his control? Just doesn’t care?
- Don’t want to be insensitive – want to help



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Relationships



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MARRIAGE FACTS



CHRONIC ILLNESS IMPACTS EVERY ASPECT OF LIFE - FAITH, FAMILIES, FINANCES, FRIENDSHIPS, EDUCATION, HOBBIES, EMPLOYMENT, AND MARRIAGE.

**3 OUT OF 4 MARRIAGES
ENDS IN DIVORCE WHEN ONE
SPOUSE HAS CHRONIC ILLNESS**



 Chronic Joy
chronic-joy.org



Meaning making
Religion
Spirituality
Existentialism



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Treatment for people w/ PD and family

Talk to family, friend, and/or medical providers



Treatment

- Talk with your doctor about medication changes
- Psychotherapy
- Electroconvulsive therapy
- Transcranial Magnetic Stimulation (TMS)
- Light therapy
- Relaxation techniques
- Massage therapy
- Acupuncture
- Aromatherapy
- Meditation
- Music therapy
- Parkinson's support group



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Daily practice



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Remember

- Pain and effort go hand in hand
- Dopamine spike needed to crave something, dip in dopamine to motivate us to move
- Did we get dopamine spike when we experienced what we wanted?
- Repeat or cease
- Wait, next dose is coming
- Don't wait until you feel like doing it



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You are not your illness

Does your illness define you?

Mindset and perspective

Everybody is dealing with something! -relationships, debt, everyone has a challenge



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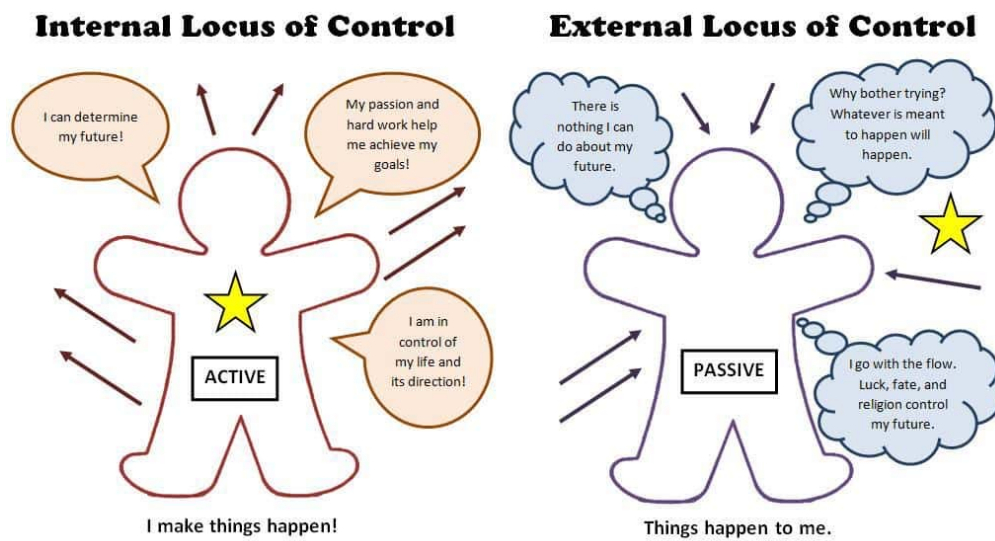
Choices

- 1) Nothing you do means anything
 - You don't have to do anything. No responsibility
- 2) Everything you do matters
 - If you make a mistake, if you betray someone, you must be responsible. Responsibility = meaning

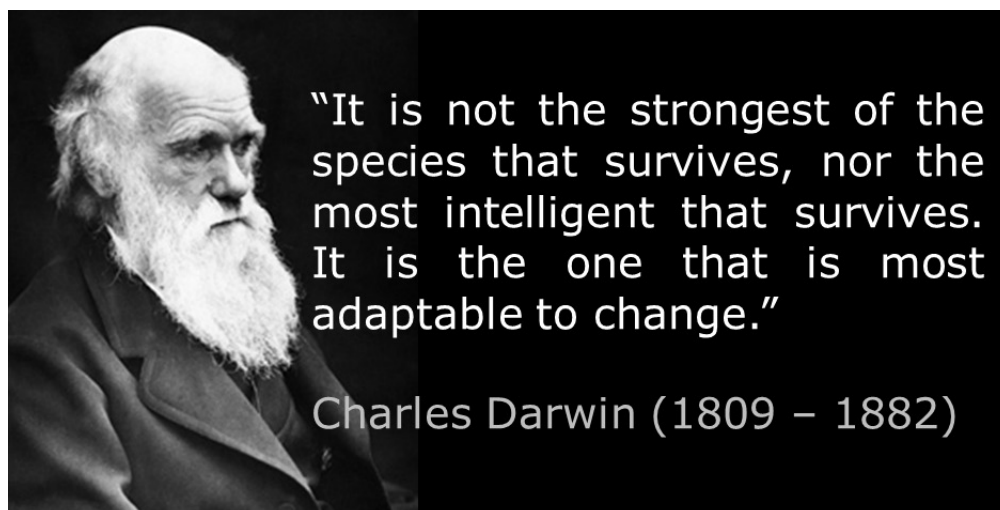


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Choices



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Reinventing your identity

New activities and new sense of self

What can we still do?

What kind of activities will support your new identity?

Reconstituting new sense of self



What we think and feel matters

Patterns of resentment, self-criticism, guilt over the past, fear over the future

Negative patterns create dis-ease

Patterns of love, joy, forgiveness are the healers



Coping with Parkinson's

**DON'T BELIEVE
EVERYTHING YOU THINK**



We developed negative coping skills because they worked to help us survive.

Create structure

- Lack of order in life can cause someone to get overwhelmed
- Do you have a job?
- Need structure and a routine
- Do not wait until you feel like doing it!
- Schedule engaging activities



Lessons learned

Being present in the here and now

Life is not about being happy

Identification of values

What matters most to you?

What do you want your health for?

Committed action in line with values



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References available upon request

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Parkinson's Disease Research, Education, and Clinical Centers

Veterans diagnosed with PD who served in-country or on the inland waterways of Vietnam between January 9, 1962 and May 7, 1975 are presumed exposed to Agent Orange or other herbicides and are eligible for presumptive service-connection.

[Agent Orange website](#) or call 1-800-749-8387, the Special Health Issues Toll-Free Helpline.

[Camp Lejeune past water contamination](#) and Parkinson's disease

[Parkinsonism](#) added to list of presumptive service connected conditions associated with Agent Orange.

[VA Military Exposures](#) and Veterans' health concerns pages

[WRIISC](#): War Related Illness & Injury Study Center, may have additional information

The Parkinson's Foundation

- Offers an extensive collection of books
- Fact sheets
- Videos
- Webinars
- Podcasts
- Parkinson.org and Parkinson.org/Veterans
- Care partners coping and resources website, book, blog

Ways to Connect

- PF Helpline Connect at 1-800-4PD-INFO (473-4636) or Helpline@parkinson.org
- PD Conversations online community forum to connect with peers
- PD Health @ Home weekly virtual educational, health and wellness programs
- VA parkinsons.va.gov
- VA Caregiver Support Program www.caregiver.va.gov or call the National Caregiver Support Line, at 1-855-260-3274.



Upcoming Veterans Webinars



June 29


Resources
for Veterans
with
Parkinson's

August 31


Veterans &
Parkinson's:
Managing Anxiety,
Depression, &
Apathy

October 26

Veterans &
Parkinson's:
Planning for the
Future

December 14

Environmental
Exposures in
Veterans with
Parkinson's

Learn more and register to attend at:
www.Parkinson.org/Veterans

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We're Here For You



Parkinson.org



1-800-4PD-INFO
Helpline@Parkinson.org



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