

PFNCA Symposium 2017
**Parkinson disease: perspectives of
patients and family**



Moderator:

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Did you suspect “Parkinson disease” prior to being diagnosed ?

In retrospect, how long were symptoms present prior to being diagnosed?

Did you believe the doctor’s diagnosis?

Parkinson disease is a “clinical” diagnosis based on the history and the presence of specific “motor” signs:

PD is often referred to as a “*movement disorder*”

“Cardinal signs of PD”:

- Slowness of movement (bradykinesia)
- Tremor at rest
- Rigidity – stiffness (cogwheel rigidity)
- Abnormal gait and posture



Parkinson patients must move “*mindfully*”

“*Automatic movements*”
are impaired in
Parkinson’s disease

gait, balance, dexterity, speech,
speed of movement



Diagnosing Parkinson disease

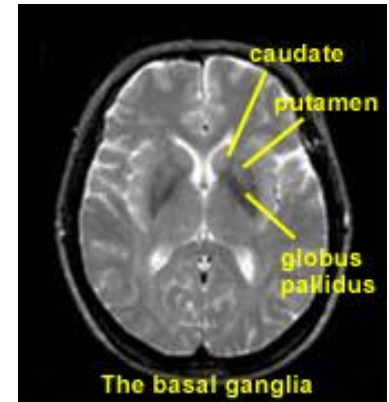
- The diagnosis is “clinical”:
(there is no definitive brain imaging study or laboratory test)

Diagnosis relies on

- Taking a complete history
- Carefully examining the patient
- Considering the differential diagnosis

Caveat:

Clinical diagnoses can change over time because of emerging symptoms



How did you react upon learning the diagnosis?

Did you start looking at internet websites or start reading about Parkinson disease? (If so, was this helpful or confusing.)

GOOGLE will give you the
haystack

but how do you
find the needle ?



Be a “cyber skeptic”

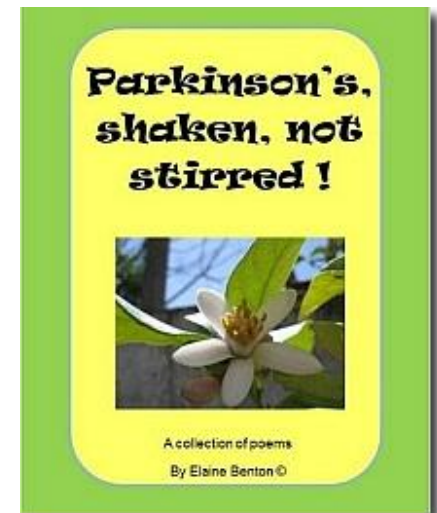
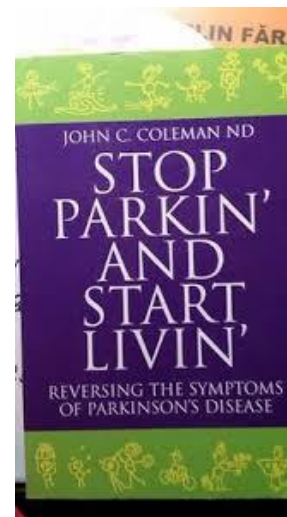
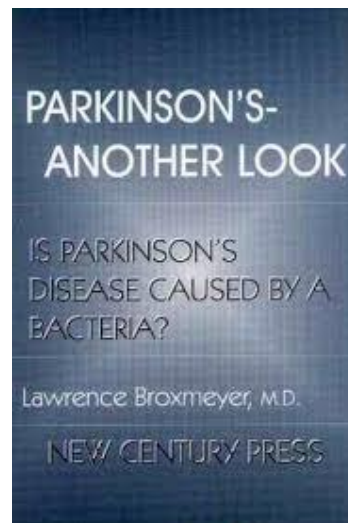
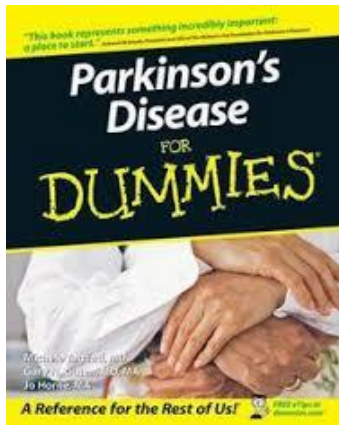
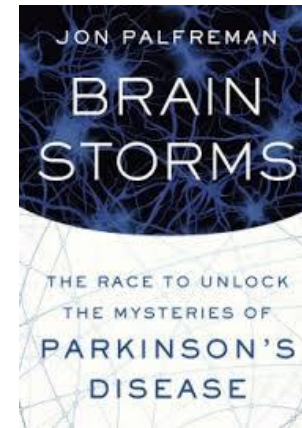
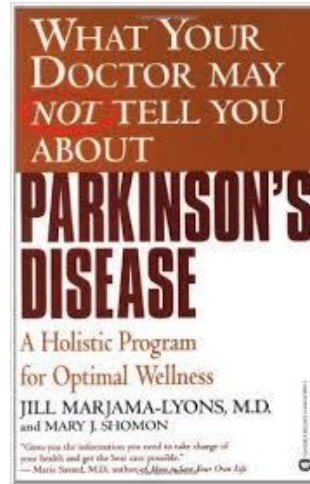
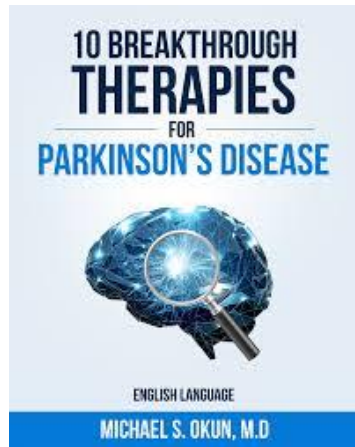
Would you drink from an unmarked bottle ?

Probably not, so consider :

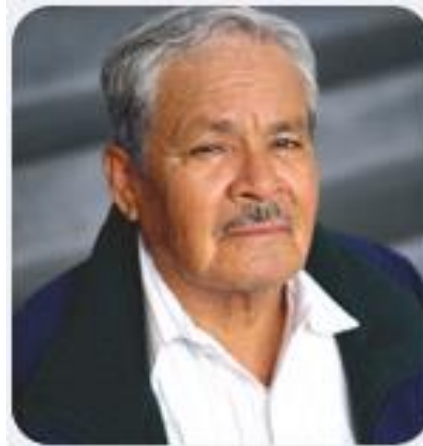
- Who is providing the content ?
- What do they know about the topic ?
- Why are they providing this information ?
- Who is funding the site ?
- Beware of sensational claims and “miracle breakthroughs”.



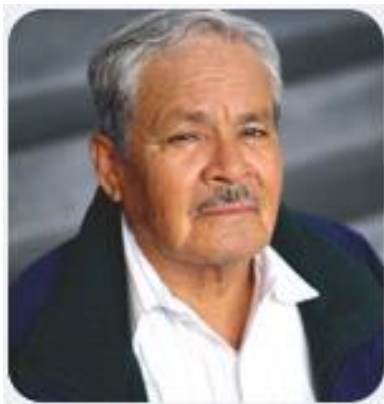
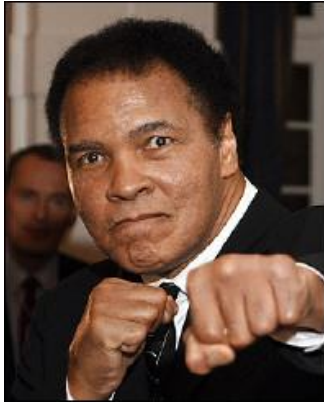
There are 100s of books about Parkinson disease (most can be skipped)



We have all heard the old saying
“if you’ve seen one, you’ve seen them all”.
However, if you’ve seen **one**
Parkinson disease patient



you've seen one
Parkinson disease patient !



There is a wide variation in the presence and severity of symptoms (“motor” and “non-motor”).

The course of the disease is also quite variable .

As Yogi Berra wisely noted:

“It is difficult to make predictions, especially about the future!”



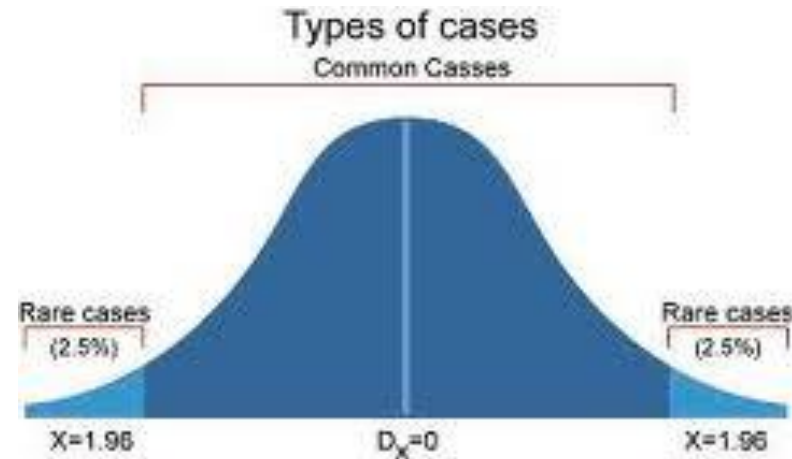
Prognosis in Parkinson disease

Patients want to know:

- **How long?**
- **How well?**

Pitfall: “it is impossible to predict with certainty”:

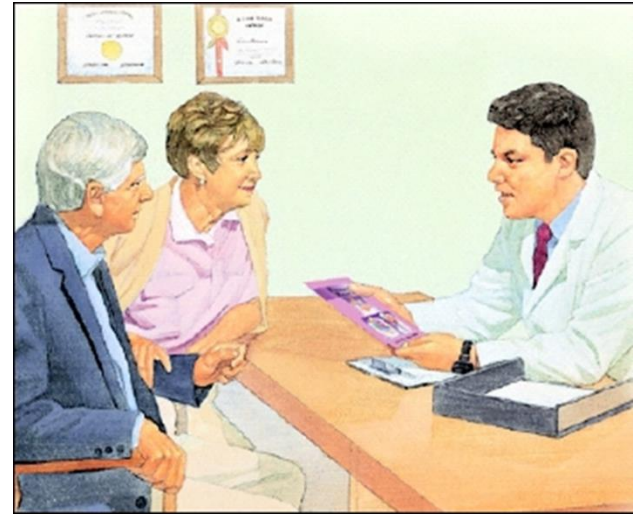
Every patient does not experience the same symptoms or problems



Did your physician do an adequate job of explaining the diagnosis, prognosis, and treatment options?

Getting the most from your visit:

- Bring an up to date list of all your medications
- Bring a contact list of all of your physicians
- If recently hospitalized or undergoing tests, bring copies of records
- Bring a list of topics to discuss to your visits



Once the diagnosis of Parkinson disease was made did you share this information with

Family ?

Friends ?

Employer / co-workers ?

If not, why not --

Divulging the diagnosis of Parkinson's disease:

“to tell” or “not to tell” ?

Do not tell:

- It is no-one's business
- I do not want people to feel sorry for me or patronize me
- I do not want people to scrutinize me
- It may affect my job or clients
- I don't want people to think I am infirm or old

Tell:

- There is nothing to be ashamed of
- There will be less stress, as I will not have to try to hide my symptoms
- People will better understand my situation
- People won't gossip about what is wrong with me



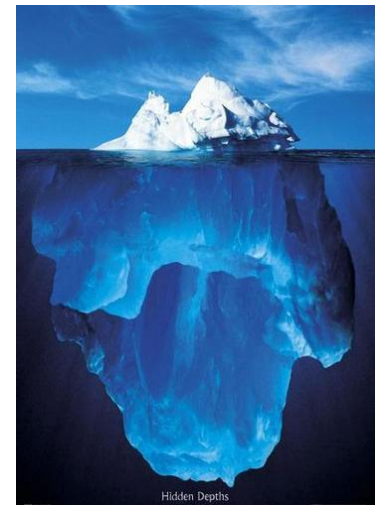
Have you been able to effectively communicate with your spouse, family, friends, and co-workers about your problems, concerns, and limitations?

Have you had an opportunity to discuss your feelings with others (including your physician) ?

“holistic” approach to PD:

Parkinsonism is generally viewed in purely “motor” terms, often focusing on “tremor” (which may be embarrassing but is seldom a cause of disability).

A more accurate approach is to broaden this view to include other “motor” as well as the major “non-motor” features that often accompany the disease.

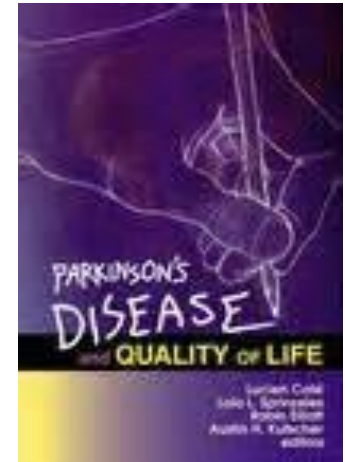


Strategies for dealing with PD

Addressing and palliating “non-motor” symptoms such as:

- Depression
- Anxiety
- Fatigue
- Constipation
- Lightheadedness
- Apathy
- Cognitive changes
- Sleep disorders etc, etc

are critical for improving the
quality of life.



It takes a team to treat Parkinson disease

- Physicians and nurses
- Exercise programs
- Educational programs (aka “support groups”)
- PT / OT / speech therapy
- Social services
- Psychological support
- Care-giver support
- Home aides



Did you begin an exercise program on a regular basis after being diagnosed with PD?

If not, why not?

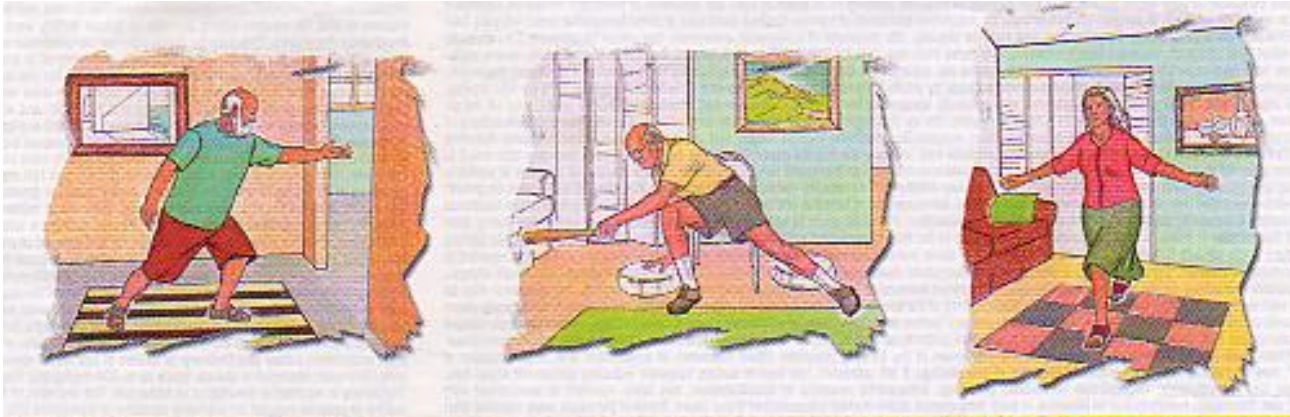
If so, do you believe this has really been helpful?

Treating Parkinson disease:

What treatment should you recommend for every Parkinson disease patient?



Exercise is an important part of the treatment regimen for everyone with Parkinson disease



Aerobic (vigorous) exercise:

- Brisk walking
- Swimming
- Treadmill / bicycle
- Dance / boxing

Sedentary exercise:

- Postural exercises
- Balance training
- Flexibility exercises

Why don't people with PD exercise? Are they being honest to themselves?

A patient recently told me:

I stopped calling the
bathroom **“the John”** and
started calling it **“the Jim”**

I get great respect when I
tell my friends that I go to
“the Jim” every morning!

Was medication for PD recommended right after the diagnosis was made?

Were you leery about the medication and after of side effects?

Were you adequately informed about the proper use of medication, and did you comply?

“Symptomatic treatment”: When should medication for treating the motor symptoms of PD be started?

- People with very mild symptoms do not require any medication**

(but might consider participating in a clinical trial of a potential “neuroprotective” agent)

However, if symptoms

- interfere with daily activity, or**
- impair balance, or**
- cause embarrassment**

then consideration for starting medication to reduce the symptoms is appropriate



Appropriate use of medication

The six “rights”:

- The right patient
- The right indication
- The right drug
- The right dose
- The right time
- The right route

The “do’s” and “don’ts” of treating Parkinson disease

Do not over-medicate patients!

also: Do not over-medicate yourself!

Over-medication can result in serious side effects

- **Dyskinesias**
- **Hallucinations**
- **Psychosis**
- **Impulse control disorders**
- **Dopamine addiction**
- **Excessive somnolence**



The “do’s” and “don’ts” of treating Parkinson disease

Do not under-medicate patients!

also Do not under-medicate yourself!

Under-medication leads to increased disability and the risk of falling.

Doses should be individualized and titrated according to the patient’s response. The optimal dose and optimal time interval between doses needs to be identified for each patient.

You can’t save the best for later!



Appropriate use of medication:

Knowledge of why a particular medication is being prescribed is the key for having physicians and patients on the same page regarding what is being treated and what outcomes are desired.

Which is a realistic goal for treating Parkinson disease?:

1. To completely eliminate tremor and all other symptoms at all times

or

2. To keep people functioning in the mainstream of life



Tremor, dyskinesia, and other PD symptoms will be intensified by

- **Stress**
- **Anxiety**
- **Excitement**
- **Anger**
- **Fatigue**
- **Mental activity**



Was the medication helpful when you first began to take it?

Were there significant side effects?

Did you have to be reminded to take medication on a regular schedule ?

What is the best medication for Parkinson's disease?



Potential side effects of dopaminergic therapy

- Nausea
- Somnolence
- Lightheadedness
- Dyskinesias
- *Psychiatric side effects:*
 - hallucinations
 - psychosis
 - impulse control disorders

DOPAMINE AGONISTS are more costly, less effective, and more likely to cause side effects than **CARBIDOPA/ LEVODOPA**



Warning Labels Can Be Hazardous to Your Health

Nov 18, 2008 1:59 PM CST

Many physicians have fallen prey
to a serious new malady:

“levodopa-phobia”



Potential side effects of dopaminergic therapy

- There are potential side effects nausea, light-headedness, sleepiness, hallucinations, psychosis, impulse control disorders

However

- Most patients tolerate carbidopa/levodopa with few or no side effects



Warning Labels Can Be Hazardous to Your Health

Levodopa: sooner or later ?

Fluctuating responses to levodopa therapy is related to the duration and progression of disease rather than the duration of levodopa treatment

“you can’t save the best for later”



When should carbidopa-levodopa be taken ?

- When starting treatment, levodopa is taken after food to reduce nausea and vomiting
- As tolerance to these side effects develops this precaution is unnecessary
- Since meals and protein delay levodopa absorption it becomes wiser to take levodopa 45 minutes prior to meals rather than afterward



a



b

Adjusting the timing and doses of levodopa is helpful but **COMPLIANCE is CRUCIAL !**

- Patients who have motor fluctuations must adhere to a very reliable time schedule for dosing of levodopa
- Doses should be taken on an empty stomach and dietary protein avoided when possible
- Use of a “timer” helps improve compliance
- The physician cannot make reliable recommendations if the patient is unreliable !



The “pill question”

Patients with Parkinson disease should be able to name their medications, doses, and intake times:

- **Inaccurate reporting suggests non-compliance or confusion**
- **Inaccurate reporting suggests that the patient cannot take their medications reliably or safely on their own and require supervision**



Patients should know their meds!

“medication use review”

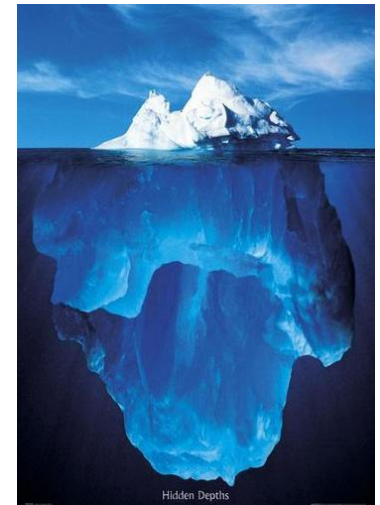
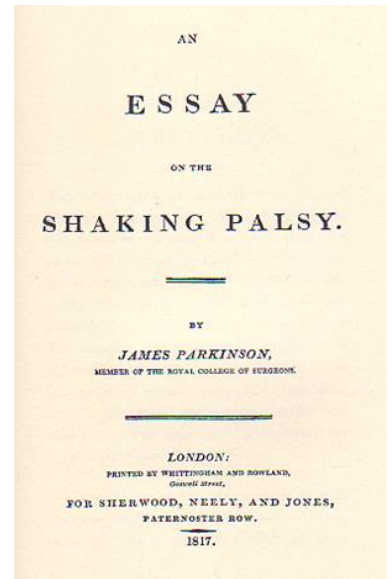
- 1. How does the medication work?**
- 2. What should I expect the medication to do?**
- 3. How do I know it is helping?**
- 4. Is it safe for me to take it?**
- 5. What are the side effects?**
- 6. What should I do if I have side effects?**
- 7. Does the medication mix with other things that I take?**
- 8. Should it be taken with food?**
- 9. What if I stop taking it or take a lower dose than recommended?**

What is the most challenging aspect of Parkinson disease for you to deal with?

How do you cope with the knowledge that you have a chronic progressive condition?

“holistic” approach to PD:

Parkinson disease is diagnosed on the basis of “motor” symptoms, but a more accurate approach is to broaden this view to include major “non-motor” features that often accompany the disease:



Parkinson disease is not just a “*movement disorder*”

abnormal movement is often just “the tip of the iceberg”

Patients often experience:

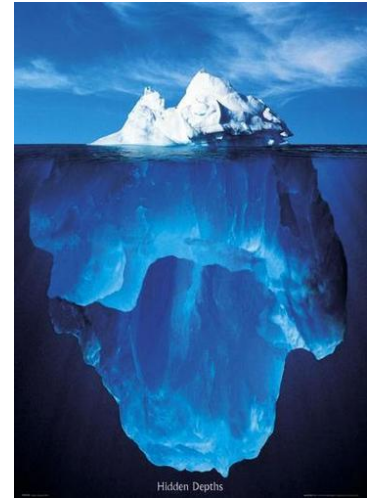
Autonomic dysfunction

- Orthostatic hypotension
- Constipation

Neuropsychiatric problems

- Depression / Anxiety
- Apathy and behavioral changes
- Cognitive dysfunction

Sleep disorders



“quality of life” in Parkinson disease



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- Parkinson disease is a “*life sentence*” not a “*death sentence*”
- In the final analysis, the “quality of life” in PD often depends as much on the management of the behavioral and psychiatric aspects as the motor symptoms

Two types of patient:

The patient who answers

“yes or no”

versus

the patient who answers

“not yet”



Human nature 201:

“Pessimists and optimists develop the same illnesses but lead very different lives!”



How do you think you are doing?

How does your family think you are doing?

**Who wins the race –
the tortoise or the hare ?**



“great moments in medicine”

Doctor:

“Your mother has had Parkinson disease for 15 years and is doing better than 90% of my patients.”

Daughter:

“I don’t care about 90% of your patients, I care about my mother!”



Assessing “quality of life” in chronic disease

In most cases feeling
“better” is not enough:

PATIENTS WANT TO FEEL

“GOOD” NOT JUST
“BETTER”.



“social phobia” in PD



Patients who are embarrassed by their symptoms, or fear that their symptoms will worsen when out of the house, become reluctant to leave the house and do not participate in social activities.

Don't let Parkinson's put you
under "*house arrest*"

"I'm too embarrassed"

"People are looking at me"

*"I don't want to make a fool of
myself"*

"I don't want to bother anyone"

"I'm afraid of falling"

"It's too much effort"

*"House arrest" is for criminals
not Parkinson patients*



Social isolation and “quality of life”

Clinical studies reveal:

- **SI is associated with lower quality of life and poorer medical outcomes**
- **SI is associated with depression**
- **SI is associated with higher mortality rates**



What are some of the “non-motor” problems that you have had to deal with?

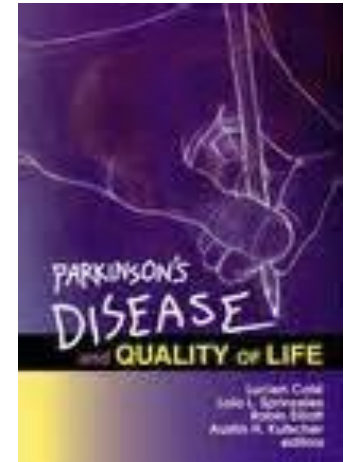
Strategies for dealing with PD

Addressing and palliating

“non-motor” symptoms such as:

- Depression
- Anxiety
- Fatigue
- Constipation
- Lightheadedness
- Apathy
- Cognitive changes
- Insomnia, hypersomnia etc, etc

are critical for improving the
quality of life.



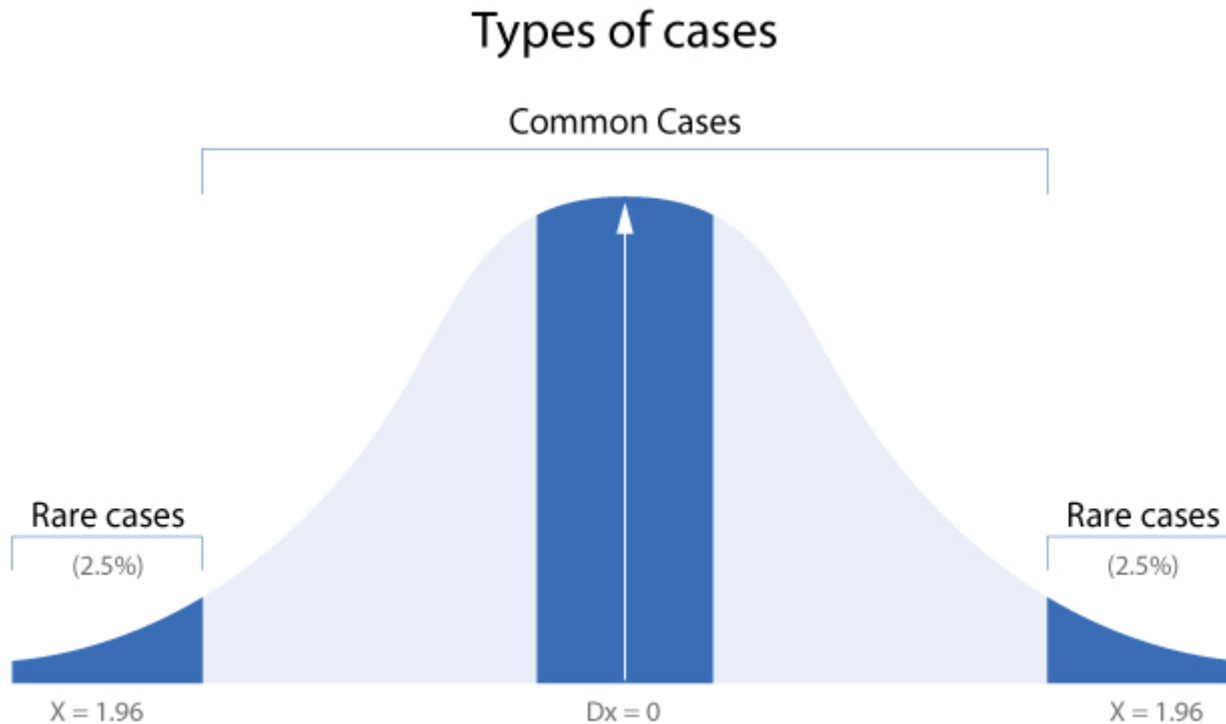
Cognitive function in Parkinson disease

Uncomplicated PD:

- Some slowing in response time
- Difficulty “multi-tasking”
- Some loss of “executive function”
- Patients remain “competent”



Every patient does not experience the same symptoms or the same problems



Cognitive function in PD

Uncomplicated PD

- Problems with memory retrieval, rapid processing, and multitasking

Parkinson disease dementia

- Sub-cortical dementia occurring years after the onset of Parkinson's disease

Dementia with Lewy bodies

- Dementia, hallucinations, and fluctuating cognitive problems occurring at the onset of PD motor symptoms



Sleep disorders in Parkinson disease

Over 80% of PD patients have some sleep disorder!

These span all aspects of sleep:

- **Falling asleep** (eg depression, RLS, anxiety, fragmented sleep)
- **Staying asleep** (eg nocturia, “wearing off”, sleep apnea)
- **Dreaming** (REM behavioral disorder)
- **Motor activity during sleep**
 - (REM behavioral disorder, PLMS, RLS)
- **Post-sleep behavior** (status dissociatus)
- **Excessive daytime sleepiness**
 - (medications, inadequate nocturnal sleep, sleep apnea)



“fatigue” in Parkinson disease

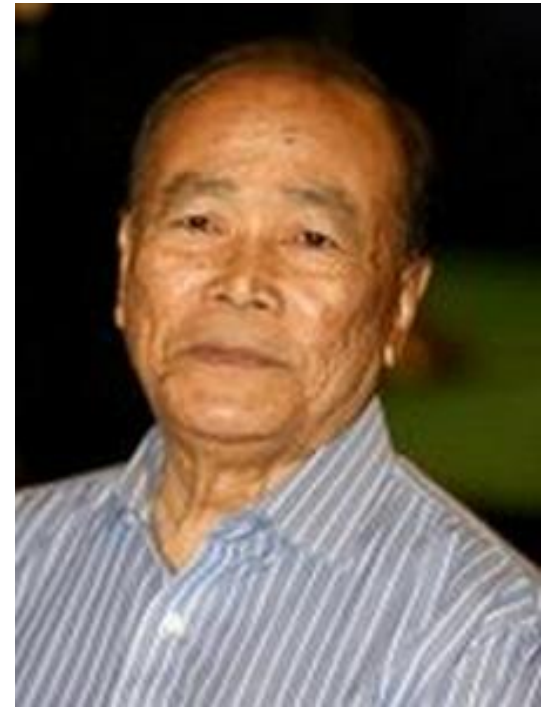
“Fatigue” is a subjective sense of

- **Tiredness**
- **Low energy**

Often associated with

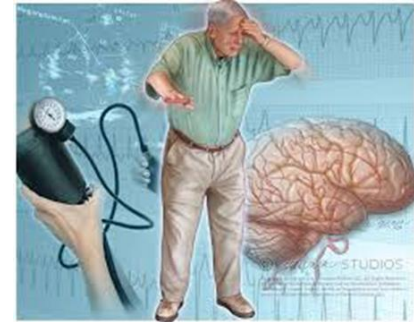
- **difficulty to initiating or sustaining activities that require physical or mental effort**

“Fatigue” is common in PD, and may be associated with apathy, depression, or cognitive decline



“Autonomic dysfunction” in Parkinson’s disease

- Constipation
- Orthostatic hypotension
- Thermoregulation
- Drooling
- Bladder dysfunction
- Sexual dysfunction
- Pain



How has Parkinson disease affected your emotional health?

Anxiety and depression are very common in patients with Parkinson disease

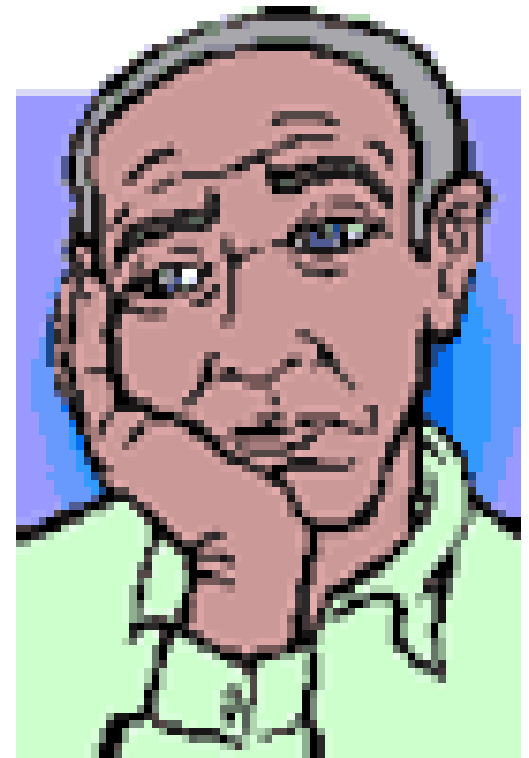


Depression and anxiety

- May precede the diagnosis of PD
- Are not necessarily related to the severity of parkinsonian motor symptoms
- Can cause great disability
- Are potentially treatable !

Emotional features of depression

- **Persistent sadness**
- **Lack of interests**
- **Lack of enjoyment**
- **Pessimism**
- **Hopelessness**
- **Negative ruminations**
- **Negative view of self**
- **Guilt**
- **Morbid thoughts**
- **Inability to cope**
- **Overwhelmed / anxious**
- **Irritability**



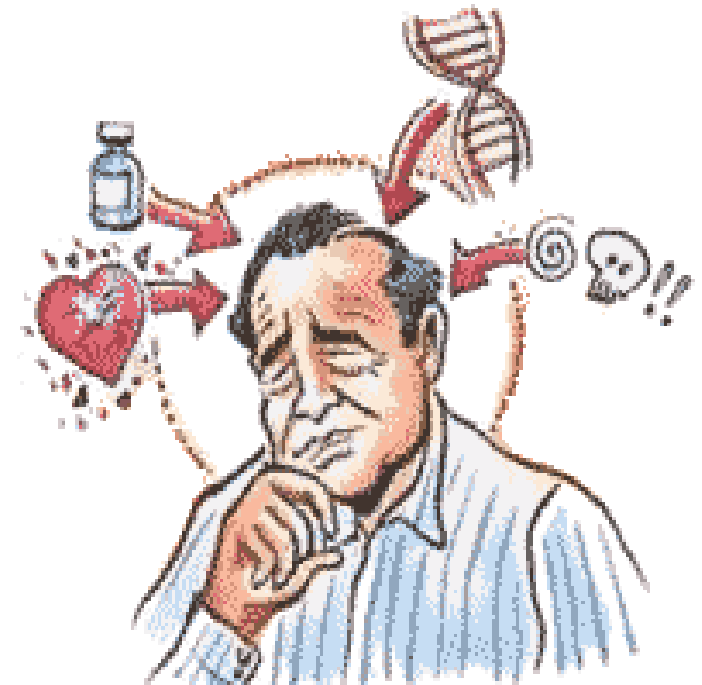
Anxiety and Parkinson's disease

Some symptoms of anxiety may *overlap* with symptoms of PD:

- Nervousness
- Restlessness
- Akathisia
- Difficulty concentrating
- Sleep disturbances
- Increased shakiness

Core symptoms of anxiety are:

- Excessive worrying
- Excessive fears



Depression and anxiety in PD are treatable:

- Optimize PD medications
- Counselling
- Exercise
- Socialization
- Support groups
- Psychotherapy
- Medications
- ECT



“APATHY” -

Spouse complains:

“he doesn’t initiate any activities”
“procrastinates”

“has nothing to say” “very quiet”
“no motivation”

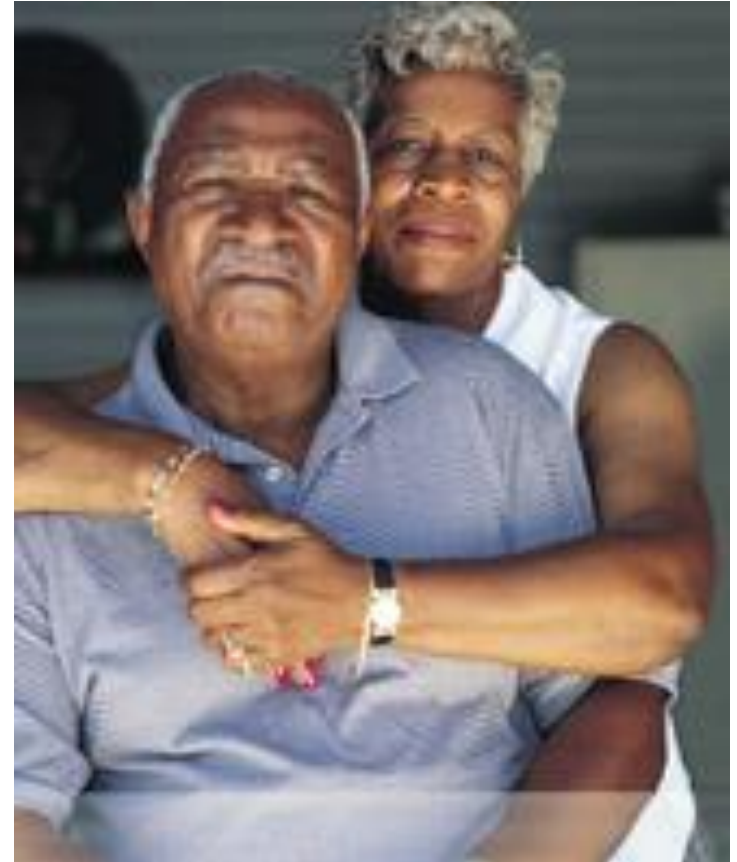
“used to be the life of the party”
“lacks interests”

“he has become a couch potato”
“disinterested” “sits like a blob”
“lack of enthusiasm”

“never gets anything done”

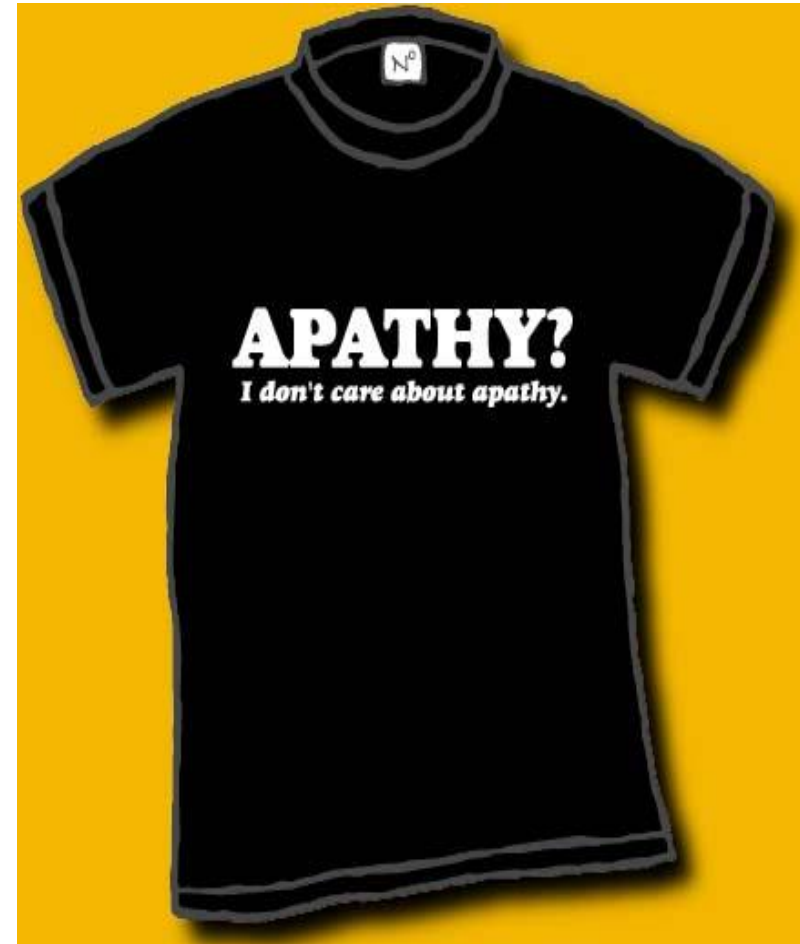
Patient says:

“I’m all right, doctor”



Clinical manifestations of *apathy*:

- Reduced interest
- Reduced participation
- Problems initiating activities
- Problems completing activities
- Slowed thought processes
- Lack of motivation
- Lack of ideas or conversation
- Loss of curiosity
- Lack of concern
- Lack of pleasure
- Indifference
- Flat affect



Is it depression and/or apathy?

The major criterion for diagnosis of **DEPRESSION** in a patient with profound apathy is the patient's

MOOD:

- Depressed patient:

inner sadness

- Apathetic patient:

emotional dullness



"Portrait of Patience Escallier"
by Vincent van Gogh

Distinguishing “apathy” from “depression”

Diagnosing “depression” requires emotional features:

- Low mood
- Reduced sense of pleasure
- Guilt
- Diminished self esteem
- Negativity
- Anxiety



"Portrait of Patience Escallier"
by Vincent van Gough

Why care about apathy ?

- Often misinterpreted or misdiagnosed
- Increases overall level of disability and handicap
- Reduces participation in daily activities
- Associated with worse outcomes and recovery
- **Increases care-giver burden and distress**



What challenges have there been serving as a care-partner?

Who has to deal with Parkinson disease?

Parkinson disease does not
just affect the patient ...
it affects the whole family!



“How does my behavior affect others?”

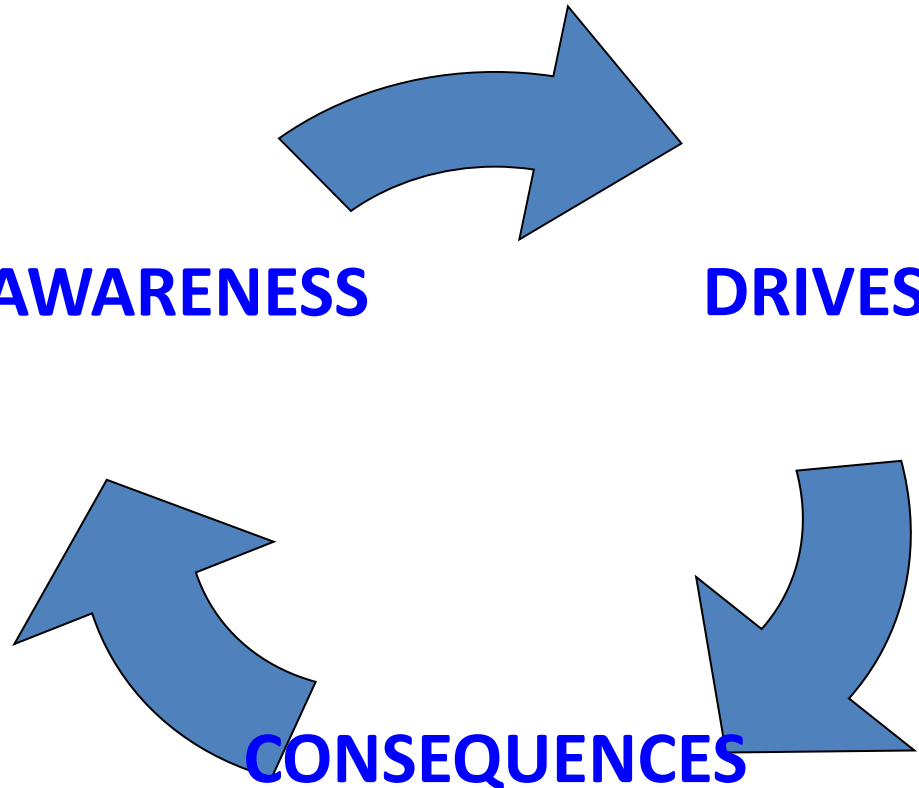
“**Lack of insight**” and “**lack of empathy**” are common cognitive deficits in patients with brain diseases. Care partners have difficulty dealing with this behavior.



AWARENESS

DRIVES

CONSEQUENCES



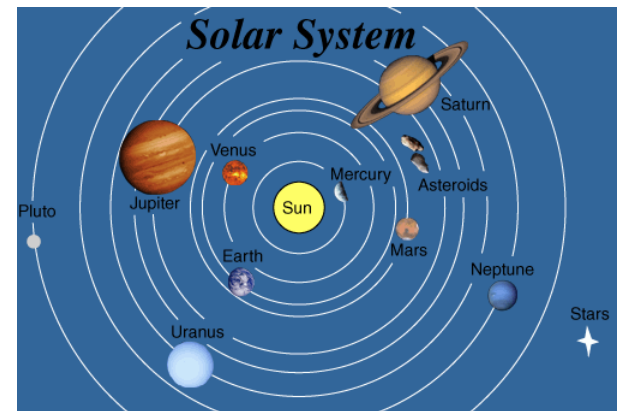
Challenges in coping with a chronic condition

- Learning to accept care and assistance without losing your sense of autonomy or self worth

You are still a **“PERSON”** and not merely a **“PATIENT”**

At the same time

- Realizing that everything in the world does not revolve around you and your condition

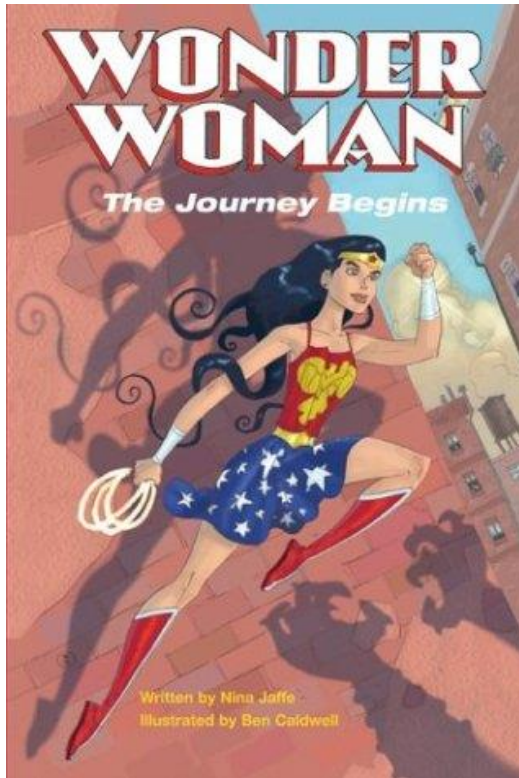


Assisting people with chronic conditions

*“Helping someone is
doing what **they** want
you to do ...
not just doing what you
want to do for them.”*



Parkinson disease has a major impact on both the patient and the care-partners:
Who cares about well being of the caregiver?
(the caregiver's health is often neglected)



A word of advice for “care partners”:



Warning signs of *CAREPARTNER BURNOUT*



Denial

Anger

Social withdrawal

Anxiety

Depression

Guilt

Exhaustion

Sleeplessness

Fatigue

Irritability

Overwhelmed

Health problems

Tips for easing the strain of being a care-partner

- Enlisting other family members to assist on a regularly scheduled basis
- Hiring aides at home for several hours on a regular basis
- Participation in exercise programs
- Participation in education seminars and support groups
- Psychological counselling
- Home safety evaluation
- Adult day-care programs



**Do not drop out of the
mainstream of life!**