

Tricks of the Trade for PD

Listed below are a number of “Tricks of the Trade” for dealing with the various symptoms found in handling Parkinson’s disease.

Overview Points:

Parkinson’s is a marathon, not a sprint!

No known cause; no known cure- creates a sense of hopelessness and “why me” attitude.

Your life is not falling apart; it’s falling into place!

Everyone’s combination and intensity of symptoms are unique.

You will have good days and bad days; just like everyone else!

Parkinson’s isn’t picking on you, it just has no rhythmic cycle. It comes and it goes.

Focus on what you can do, not on what you cannot!

Parkinson’s appears to take things away from you, especially your sense of independence.

C.H.E.E.R.S

Community- April is Parkinson’s Awareness Month- City/ State Proclamations

Groceries Community Rebate program

Elementary School reading programs- Side Kicks

Knitting for Under privileged or elderly

Hope- Sing Loud for PD (APDA)

Faith based activities – Mission Trip clean up

Exercise- $220 - \text{Your age} = \text{Max Heart Rate per minute}$. 65 – 75% of Max rate for 30 minutes

Dancing – Tango 6 count music

Boxing- Spell your grandchildren’s names

Virtual Golf Swing

Biking/ Running/ Walking with Sticks in various races to raise funds

Education- Parkinson’s Numbers 6M in world; 1.1M in USA; 64K in Florida

Parkinson’s Costs- \$52B; \$26B medical costs; \$26B Lost Opportunity; Feds \$28B

PD History- 1817 Dr James Parkinson through today

Parkinson’s 101- C.O.I.K. words (Lewy Bodies; Dopamine);

Research- Topaz/PPMI/ 23 & Me/ Gene-eration
MJFF/ ClinicalTrials.Gov/ National Foundations
Self-Efficacy- Think Globally, Resource Regionally, Act Locally (PAR, DPF, Jax Hope)
Contact your Senator/ US REP/ City Council/ EPA

Patient Oriented Outcomes-

Dr Laurie Mischley measure your progression, see your score
Parkinson's Life Assessment process

Grit scale- Dr Angela Ductworth

Make it Fun-

PD Bingo

Rewards System- Earn points for correct behavior. 7 days of "action" = 1 "Atta Boy"

3 "Atta Boy" = Redeem for "goodie"

Motivation-

Influence with Integrity vs Manipulation.

Mental Trickination:

Intrinsic vs Extrinsic motivation- who you do it for (Grandchildren)

Everyday is better than T, Th. Repetition is the mother of learning.

Consistency of training is more important than intensity of reward

Four levels of Learning- UI, CI, CC, UC 10,000 hours

Tactic; Trait; Habit; Bent; Lifestyle

Getting Out of a Rut-

Start Streaks of Activity. Humans hate to break streaks. Put X on Calendar for accomplishing task (exercise/ voice/ etc).

PTO Days- 30 days of "X" activity = 1 Day Off

AA Green Card- "Just for Today"

Home Safety-

Install lever handle door knobs

Watch various surface transitions (rug to wood floor to threshold)

Tall Toilets with grab bars
Step in Shower
Tall backed chairs with raising Armrests
Items on stairs for visual alertness
Texture added to slick surfaces (ceramic tile)

Tactical Applications for PD

Motor Symptoms-

Tremor/Dystonia/ Bradykinesia:

Look for opportunities to use tremor: ice tea, erasing, painting. Fishing rig set up. Avoid anxious situations. Hand exercises/ dexterity. Velcro vs buttons. Pull on shoe vs tying knots. Elastic waist vs buckle belts. Pickup coins/ buttons, make shapes

Balance Issues:

Use all three forms of balance: Visual, Vestibular, Otoconia hairs

Dancer's Spin: Posture; Imagine head on a String; Pull straight up (ice skater's spin)

Points of Contact: More are better than few (3 better than two) Shower; 4 better than 3

Micrography:

Lined Paper. 2nd grade capitals writing paper. Special shaped pens and pencils. Think big!

Use colored pens, your eye notices it more. Print verses cursive.

Therapeutic Writing calms your nerves. Letters to Grandchildren.

Soft Voice (Hypophonia):

L.S.V.T or Speak out, Sustained phonation – 20 second Loudest "AHHHHH", Raspatory

Resistance training

Swallowing:

Texture of food, 30X Big Effort Swallowing 3X/day, Extra chewing time

Akinesia:

Dead Arm Swing, watch shadow, keep something in your hand

Hypomimia:

Dead pan facial expression, facial exercises, care giver signal

Exercise:

Walk/ Run/ Bike/ Box/ Dance for a cause; Endorphins; Accountability Coach; Go on a walk to talk about favorite topic (Travels / G -Kids), SUP Paddle boarding (balance)

Non- Motor Symptoms:

REM/ Insomnia/ Night Terrors (Poor Sleep):

Learn to improve sleep hygiene. 7 hours in a rolling 24 hours. Napping. Go to sleep at The same time (Circadian rhythm). Stop TV, computer screens, Blue Lights sources 30 Minutes before bed. White noise. Calm your mind. King size bed. Papoose yourself.

Constipation:

Recipes for regularity. Stay hydrated (33% of body weight in fluid ounces per day). Watch diet (rice, oatmeal, etc). Eat more fruits and veggies; less meat; more fiber. Learn Colon massage therapy. Watch RX taken (Amantadine). Exercise “ to go”

Olfaction (Loss of sense of smell):

Remember the smells, Caregiver awareness

Anorexia (Weight Loss):

Watch Diet, Caloric intake

Hypersalivation:

Cough drops, gum, buttons

Psychological Symptoms:

Anxiety:

Therapeutic Writing- Poetry, Letters to your G-Kids, Pen Pals with prisoner, ABC Love songs; Nature/ Flowers/ Gardening; GRIT scale; Participate in studies (23 & me);

Honorariums to 529 account.

Apathy:

Plan for the Day; Power of defaults (Ie 401K); Daily Specials (word for the day); Meta Cognition- your thoughts about your thoughts (Why am I sad?) Focus on Blessings and Victories; Parkinson's Life Assessment (keep track)

Depression:

Knit for under-privileged; focus on Faith (Rom 8:28, Jer29:11 -13); Placebo affect: Setting/ Theater/ Conditions (Pills better than massage; injections better than pills; Surgery better than injections); Brand recognition better than generic

Socialization:

Support group; Run from isolation; Quarterly lunch (Zoom) with friends; " A Father's Legacy"; Write politicians on pesticides; Symposiums PAR's E3; Sidekicks

Focus on what you can do:

Puzzles; Mind games; Long term memories; Recall 1956 Year books

Start something new:

Archery; 14'ers; Write book; Study WW II history; Pick a topic (pirates); mosaic stones