

SELF-CARE FOR PARKINSON'S CARE PARTNERS: DEVELOPING RESILIENCE

TIME OUT FOR CAREGIVERS
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CAREGIVER/CARE PARTNER

“There are only 4 kinds of people in this world. Those who have been caregivers, those who currently are caregivers, those who will be caregivers, those who will need caregivers.”
(Rosalynn Carter, 1st lady 1977-81)

OUTLINE #1

- Self Care
- Balancing PD and life
- Communication
- Making a care plan
- Managing care team
- Care options
- Resilience

A CAREGIVERS BILL OF RIGHTS

I have the right:

- To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.
- To seek help from others even though my loved ones may object. I recognize the limits of my own endurance and strength.
- To maintain facets of my own life that does not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.
- To get angry, be depressed, and express other difficult feelings.
- To reject any attempts by my loved one (either conscious or unconscious) to manipulate me through guilt, and/or depression.
- To receive consideration, affection, forgiveness, and acceptance for what I do, from my loved ones, for as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full-time help.
- To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting caregivers.

THE IMPORTANCE OF WELL-BEING

Health is a balance of positive and negative aspects

- Being prepared, assuming the role and being realistic
- Good relationship quality
- Make it a meaningful experience

CAREGIVER SELF-CARE

- **Sustain Yourself**
- **Establish Priorities**
- **Set Limits/Boundaries**

CAREGIVER SELF-CARE

- **Health**
 - Up-to-date with your own health needs
- **Nutrition**
 - Eat well
- **Avoid Fatigue**
 - Respite-Relaxation-Recreation
- **Sleep**
 - Find rest for body and mind and maintain a consistent schedule
- **Time Management**
 - Daily/weekly to-do lists and prioritize tasks, break up tasks into smaller ones
- **Connect with Others**
 - Meaningful social support AND find joy in time with PWP

CAREGIVER SELF-CARE

- Problem Solving
 - Be flexible and creative
- Take Charge
 - Control how you feel about a situation and behave
- Set Limits
 - Boundaries on time and energy
- Ask for Help
 - Get help early and look into available options
- Avoid Multitasking
- Self-compassion
 - Caregivers' jobs are one of the hardest, so be kind to yourself. Talk to yourself like you would talk to a best friend. Extend support, be non-judgmental and know that you are not alone.



CAREGIVER SELF-CARE STRATEGIES

- Stress management
- Exercise
- Breathing and Relaxation Techniques



BALANCING PARKINSON'S AND THE REST OF YOUR LIFE!

- Work-life Balance
 - Balancing care responsibilities with time for oneself and self-care
- At work:
 - What are the programs and policies available to you?
 - Speak to supervisor and/or HR to create action plan
 - Speak to co-workers
- At home:
 - Make time for activities
 - Make time for your own medical and health needs
 - Make a plan for care options

TALKING ABOUT PARKINSON'S

- Often hidden from public at first
- Communication is KEY to understanding
- When sharing news of diagnosis
 - Prepare
 - Time your delivery in an appropriate situation
- As a caregiver, find a support group and or someone you can talk openly with

INTENTIONAL CONVERSATION

- Minimize distraction
- Look at each other – speak up if your voice is soft
- Pay attention
- Wait until speaker finishes before responding
- Keep an open mind
- Avoid being defensive
- Avoid advice auto-pilot
- Practice!

MAKING A CARE PLAN

- Needs to account for progression and unpredictability
- Plan frees up energy to enjoy the good times (preparedness!)
- Different situations/facilities

MAKING A CARE PLAN IS SELF-CARE

- Preparing for the future for the future frees up energy to enjoy the good times still to come in your life.

**BUT BE
FLEXIBLE!**



MAKING A CARE PLAN

- At home:
 - Level of current ADL care
 - Medication
 - Safety of environment
 - Transportation
- Home assessment plan

MAKING A CARE PLAN

- In the Hospital
 - Routine or emergency situations
 - Discharge
 - Record care plan + contact info in notebook
 - Hospital protocols and care
 - Contact staff admin
- Ask questions
- Be prepared to answer questions related to treatment decisions
- Know your values
- PSBC Aware in Care kits re. medication education

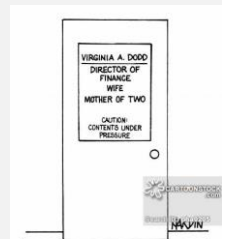
MANAGING YOUR CARE TEAM

- Caregiver, CEO
- Building your Care Team
- Organizing information



MANAGING YOUR CARE TEAM

- Caregiver, C.E.O.
 - What is your mission statement?
 - Who are your board of directors?
 - What is your meeting and work schedule?



MANAGING YOUR CARE TEAM

- Building a Care Team
 - Movement disorders specialist, neurologist or general practitioner, Nurse/nurse practitioner, Physiotherapist, Occupational therapist, Speech language pathologist, Pharmacist, Social worker/counsellor, Dietitian, Psychologist/psychiatrist
- Include family and friends (board of directors!)
- Delegate responsibilities according to ability and availability
- **CAREGIVING IS KNOWING WHAT NEEDS TO BE DONE AND WHO TO CALL TO HELP YOU DO IT.**

MANAGING YOUR CARE TEAM

- Organize Information
 - Create your own organization system to keep track of your HC team, scheduled appointments, activities, medication, hospitals, bills, and insurance.
 - Have a calendar
 - Designate a drawer
 - Tell someone else about your system

GETTING OUTSIDE HELP

- Create Healthy Boundaries
 - Set limits to encourage your own self-care
 - "I can only do this much"
- Prioritize
- Encourage independence in PWP

GETTING OUTSIDE HELP

- Respite
 - You may need an occasional break, or are unable to provide safe and effective care at home anymore.
 - Hardest decision you've likely had to make
 - Seek support to manage your own feelings during transition
 - Local health authority & request an assessment for home and community care services for publically funded option
 - Intake assessment
 - Care manager
 - Home assessment
 - Hire professional caregiving for privately funded option
 - For housing care in BC, families asked to ID preferred housing location. Expectation is you'll take first available bed (48hrs) *PLAN

GETTING OUTSIDE HELP

- Types of Support:
 - Community Nursing (education, medication, wound care, palliative)
 - Community Rehab (PT, OT, physical function, home)
 - Adult Day Services (therapeutic social and rec activities)
 - Home Support (ADL)
- Independent housing (retirement, independent living)
- Assisted Living (housing, hospitality, personal care)
- ST Residential Care (<3 months, respite, convalescent, hospice)
- LT Residential Care (24hr supervised care)



RESILIENCE

“The ultimate measure of a man/woman is not where he/she stands in moments of comfort, but where he/she stands at times of challenge and controversy”
Martin Luther King Jr.

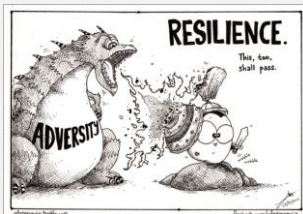
RESILIENT PEOPLE KNOW THEY HAVE CONTROL OVER THEMSELVES IN THE PRESENT MOMENT

CHARACTERISTICS OF RESILIENCE

1. Able to adapt to change healthfully
2. Feel in control of one's life
3. Know and rely on your own strengths
4. Have close, dependable relationships
5. Know where to turn for help, and ask for help
6. Remain optimistic
7. Persevere
8. Savor the moment
9. Be ok with un-comfort and uncertainty
10. Find meaning in what happens
11. Come to like challenges

RESILIENCE

- What are your top 3 signature strengths?
- Who is in your "life raft"?



SUCCESSFUL SUSTAINABLE TRANSFORMATION

1. Start with ONE thing
2. Integrate it immediately
3. One day at a time
4. Tell someone in close to you
5. Track your progress
6. Reward yourself

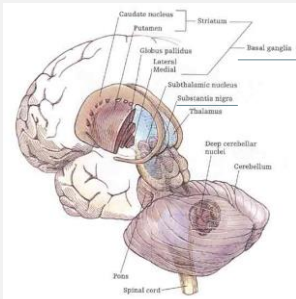
PREPARING FOR MEDICAL APPOINTMENTS

- P – present detailed information about feeling
- A – ask questions if info is not provided
- C – check your understanding
- E – express concerns about recommendations
- Come prepared.
 - Bring top 3 items written down
 - Track medication/wearing off. Bring up any issues.
 - Check prescriptions for refills
 - Note changes in living situation and/or care (i.e. speech therapy)

OUTLINE #2

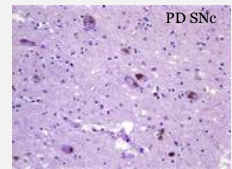
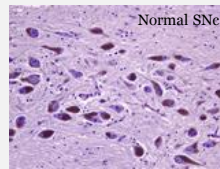
- PD pathology
- Non-motor challenges
- Memory
- Mood
- Communication
- Sleep

PD: NEUROANATOMY



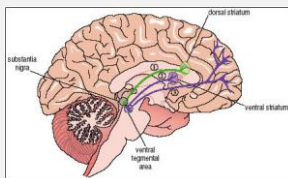
PD: NEUROCHEMISTRY

- Depletion of neurotransmitter dopamine
- 80% of dopamine found in "striatonigral complex"
- Primal source= substantia nigra pars compacta (SNc)



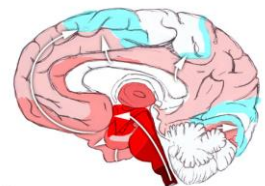
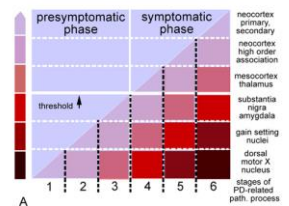
PD: PHYSIOLOGY OF BASAL GANGLIA

- Disruption to dopaminergic nigrostriatal projections interferes with motor circuit function of basal ganglia



PD: PATHOLOGY (CELL LOSS)

- Braak staging (from brain stem to cortex)



PD: PATHOLOGY (CELL LOSS)



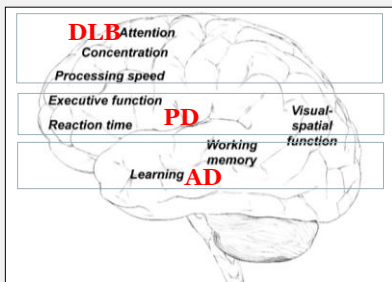
PD: PATHOLOGY (LEWY BODIES)



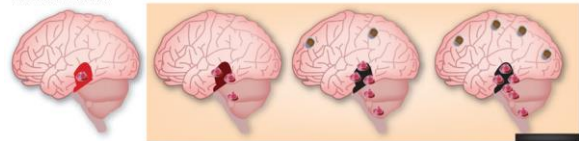
Micrograph of brain cells containing a Lewy body, which is an abnormal aggregation of protein.

PD: PATHOLOGY (BRAIN REGIONS)

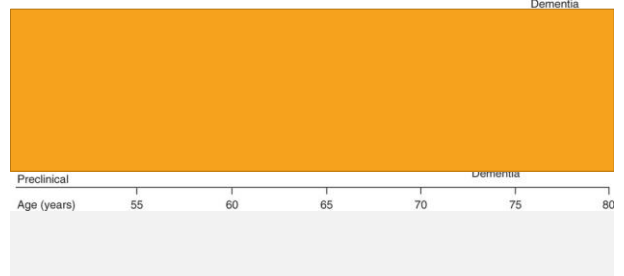
- Damage to brain cells and inability for cells to communicate
- Particular brain region associated with function



Parkinson's disease



Dementia



NON-MOTOR CHALLENGES

- Mind, mood and memory
- Non-motor challenges pose greater risks for PWP and caregivers
- Daily life

SIGNS OF COGNITIVE DECLINE

- Forgetfulness
- Fluctuating attention
- Difficulty concentrating
- Difficulty with information retrieval
- Slow thought process
- Altered judgment and changes in perception
- Visuospatial difficulties
- Difficulty with word-finding, articulation
- Difficulty making decisions
- Difficulty with planning and sequencing
- Difficulty with problem solving
- Hallucinations
- Behaviour changes (i.e. aggression)
- Depression
- Anxiety
- Apathy
- Sleep disturbances

MEMORY

- **Encoding** or registration: receiving, processing and combining of received information
- **Storage**: creation of a permanent record of encoded information
- **Retrieval**, *recall* or *recollection*: calling back the stored information in response to some cue for use in a process/activity
- In Parkinson's:
 - poor free recall/retrieval; retain recognition
 - internal memory search strategy? *dysexecutive function
 - memory distortion

EXECUTIVE FUNCTION

- Conductor of the brain's orchestra
- Goal-directed behaviours: managing oneself and the resources necessary to achieve a goal (i.e. mental control, self-regulation)
 - Planning
 - Purposive action
 - Effective performance (self-monitoring)
 - Volition (problem solving, multi-tasking)
- **In Parkinson's**
 - Sequencing
 - Planning
 - Goal-directed behaviour

ATTENTION

- Focused: actively focus on one thing without being distracted
- Divided: the ability to respond to multi-tasking
- Sustained (vigilance): directed focus for the duration of a task
- **In Parkinson's**
 - Difficulty in maintaining focus while ignoring competition stimuli (focused)
 - Multi-tasking difficulties may show up as gait dysfunction and falls
 - Vigilance may show up as drowsiness, staring into space, long daytime naps, disorganized speech

BRADYPHRENIA

- Slowed thinking
- May say their brain feels "swampy"
- Takes longer for them to complete tasks
- Takes more effort than usual to complete tasks

TIPS FOR COGNITION

- Establish a regular schedule and post it in a calendar
- Use reminders
- Write to-do action lists and include timelines and/or instructions
- Place lists and/or instructions by the task-at-hand or item
- Reduce clutter
- Keep items in the same labeled place
- Get active – physically, mentally and socially!
- Use medication if you need it

YOUR THOUGHTS?

MOOD CHANGES

- Mood is an internal emotional state
- 50% of PWDs experience depression and/or anxiety
- Changes in mood occur due to variety of reasons
 - Reaction to diagnosis
 - Reaction to symptoms
 - Thinking about future
 - Brain pathways affected
 - Side effect medication

MOOD CHANGES

- In Parkinson's disease, depression and anxiety can contribute to the worsening of motor symptoms, gait difficulties, freezing, on-off fluctuations, cognitive decline, and quality of life. As a caregiver, this makes it an important non-motor symptom to pay attention to.

TIPS FOR MOOD

- ID and name emotions
- Schedule only shorter meaningful activities with breaks
- Notice patterns and ensure adequate sleep
- Avoid coordination or attention tasks
- Caregiver support group
- Professional counselling

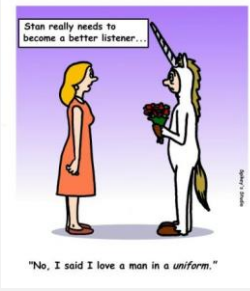
YOUR THOUGHTS?

THE PERILS OF MISCOMMUNICATION



COMMUNICATION STYLES

- Controller
- Peacemaker
- Negotiator
- Passive aggressor



COMMUNICATION CHALLENGES IN PD

- Word recall (bradyphrenia)
- Word finding (naming)
- Impaired comprehension of complex sentences
- Articulation, voice, tone

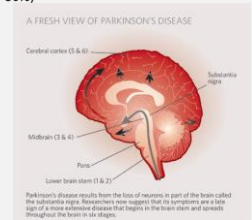
TIPS FOR COMMUNICATION

- One-one-one with eye contact
- Reduce distractions
- Speak slowly,
- Non-verbal communication
- Communicate during ON
- Encourage PWP to think LOUD
- Ask if you can provide cues
- One question at a time and closed-ended questions
- SLP trained in LSVT® (lsvtglobal.com)

YOUR THOUGHTS?

SLEEP

- Hypocretin cell loss
- Predate Parkinson's diagnosis? (33-60%)
- Suggestive item in DLB diagnosis (50-80%)



SLEEP

- Sleep-wake cycle disturbances
- REM sleep behaviour disorder
- RLS
- Daytime sleepiness

TIPS FOR SLEEP

- Be active during the day
- Adjust mattress and pillows for comfort
- Bed height, against wall and/or raised head of your bed
- Separate covers for you and your bedmate with PD
- Separate bedrooms for you and your partner with PD
- Bedside commode, urinal or bedpan
- Throwaway mattress protection pad
- Trapeze bar to transfer
- Bed rails or study chair to get in/out bed
- Silk sheets for turning in bed
- Sleep hygiene and consistent routines

YOUR THOUGHTS?

THANK YOU!