

# Care for the Caregiver

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Caregivers come in all shapes & sizes....



# The Journey

- Unexpected journey starts with diagnosis of Parkinson's
- Help you find a way through maze of road signs, turns, smooth & bumpy rides, side trips & sudden detours



## Beginning: Starting out

- Starting journey requires planning, maps, gathering supplies, preparing for trip
- Early PD requires little caregiving
- Good time for education about PD
  - Attend lectures (like today)
  - Go to MD visits with loved one
  - Ask questions (write down before)
  - Info in libraries, internet, PD organizations

## Beginning: Evaluation

- Evaluate present situation: Assess
  - Loved one's needs
  - Home environment
  - Your health, emotional state, commitments
  - What you can & can't do yourself
  - What outside support needed
  - Financial issues: health insurance, employment, paying bills, power of attorney

## Beginning: Have a Family Meeting

- Reasons/Benefits
  - Helps everyone understand present & future situation
  - Have early in process, but never too late
  - Meet in person, but phone conference ok
  - Include person with PD? Good if possible

## Beginning: Family Meeting

- Tips for a good meeting:
  - Plan ahead, prepare, give alternate dates
  - Written agenda
  - Facilitator: trusted clergy, social worker
  - Describe caregiving situation clearly
  - Allow time for absorbing what's been said
  - Get feed back but some may be in denial, nervous or defensive

## Beginning: Family Meeting (cont.)

- Ask for help (they can do something no matter how small or how far away they live)
- Review what' been decided & when next meeting will be
- Agree to stay in touch
- End with shared meal you didn't prepare

## Staying on course: Take Care of Yourself

- “Your own good health is the best present you can give your loved one” \*
- Maintain mental & physical health
  - Make & keep medical & dental appointments
- Keep your job whenever possible
- Join a Support Group for Caregivers

\* Suzanne Mintz, President, Co-founder NFCA

## Staying on course: Take Care of Yourself (Cont.)

- Get your sleep (even if PD person can't)
- Take breaks—get-a-ways & mini-breaks
- Make & keep social activities
- Make & keep spiritual activities
- Keep (or develop) sense of humor

# Traveling Companions: Get Help

- Benefits

- Lessens feelings of isolation
- Encourages independence of loved one
- Gives you more confidence
- Increases your creativity
- Helps you get those needed breaks



## Barriers to Getting & Accepting Help

- Americans are independent & private
- Outside help exposes our private lives to the public
- Care receiver doesn't want help
- Finding help can be hard for emotional, financial, & geographic reasons

## How to Define & Get Help

- Caregiving is a Job with individual tasks
- Asking for help is sign of strength, not weakness
- Make a list of caregiver tasks in typical week
- Organize list into categories
  - Caregiver needs & how people can help
  - Decide what to let go & what to keep

## Caregiving Tasks Example

Caregivers Needs	How friends/family can help
Ride to MD	Chauffeur Service date/time
Make dinner	Meal prepared & delivered
Insurance company	Forms filled out & advocate
Keep house clean	"Maid brigade"
Keep food in house	Grocery shopping per week
House maintenance	Handyman, kid to mow lawn

## Asking for Help

- Start with something small & specific
  - Pick up rx at drug store
  - Gets easier with practice & your task list
- Accept offers of help
  - “Call me if you need me,” Say Yes!
  - People really want to help
- Realize sometime you maybe disappointed

## Where to get help: Resources

- Local & Community
  - Free to low cost: Neighbors, friends, churches, synagogues, senior centers, adult day health, Meals on Wheels, door-to-door vans
  - Fee based: In-home care (helps with cooking, bathing, dressing, meal prep, etc.)
  - Social Worker from health plan or hospital (VA) can connect you



## Where to get help: Resources State & National

- Family Caregiver Alliance: San Francisco
  - [www.caregiver.org](http://www.caregiver.org)
- National Family Caregivers Association
  - [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)
- American Parkinson's Disease Association
  - [www.apdaparkinson.org](http://www.apdaparkinson.org)
- National Parkinson's Association
  - [www.parkinson.org](http://www.parkinson.org)
- Michael J. Fox Foundation
  - [www.michaeljfox.org](http://www.michaeljfox.org)
- Each website gives more sources & other websites

## Journey gets Bumpy--Advanced Parkinson's Caregiving



- Respite care
  - Temporary care in nursing home—day or week at time
  - VA provides 6 weeks/year at no cost at SFVA or Menlo Park
  - You both get needed break

## Journey gets Bumpy--Advanced Parkinson's Caregiving (cont.)

- Care out of home
  - Often difficult decision
  - Not a failure of caregiver
  - Realization that care required is beyond what caregiver can provide
  - Caregiver remains caregiver but level & type changes
  - Caregiver becomes patient advocate & overseer of care provided

## Journey gets Bumpy--Advanced Parkinson's Caregiving (cont.)

- Options for care out of home
  - Continuing Care Retirement Community
    - Covers all levels of care but expensive
  - Assisted Living Facilities
  - Board & Care--usually small, more personal
  - Nursing homes (custodial care)
  - Hospice Care—VA provides at no cost, other health care groups also provide (Kaiser)

## Review of the Journey--Recap

- Preparing for trip with education, evaluation, preparation, family meeting
- Staying on course—Caring for yourself—your gift to care receiver
- Important traveling companions—for help you need, how & where to get it
- Options when road gets bumpy & PD advances—out of home care

## The Best Results

