

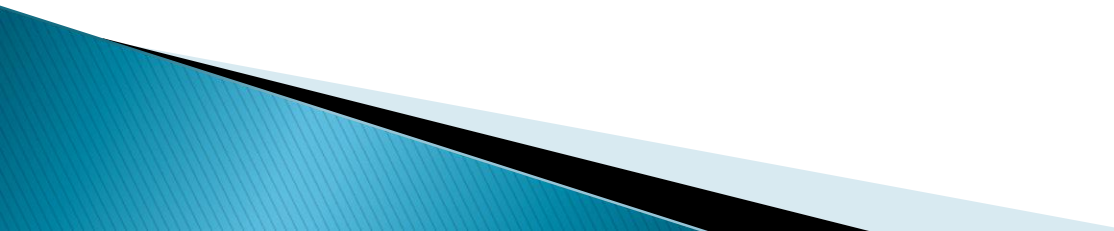
# Caregiving and Psychosocial Issues in Parkinson's Disease

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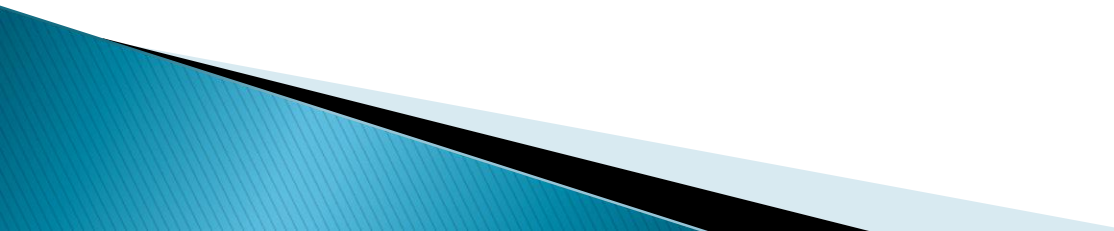
San Francisco Veterans Affairs



# Parkinson's Disease & Caregivers

- ▶ PD is a chronic, progressive neurological disease, characterized by tremor, rigidity, bradykinesia, & postural instability.
  - ▶ PD prevalence is projected to affect 1.3 million by 2040 (Lilienfeld & Perl, 1994)
  - ▶ Only about 7% of PD persons are admitted to long-term care facilities; most are cared for by families at home (Mitchell, Kiely, Kiel, & Lipsitz, 1996)
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# Who are Family Caregivers?

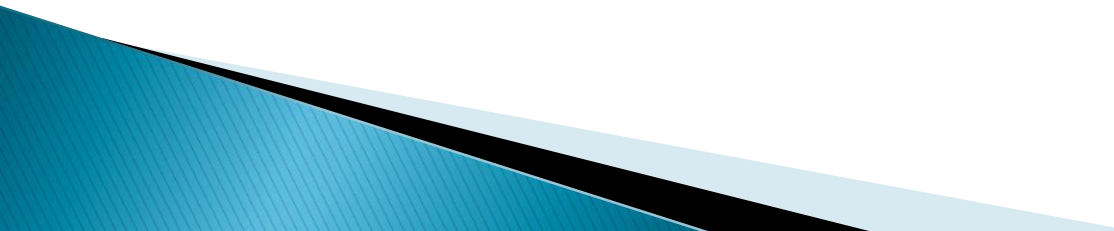
- ▶ Those who provide a wide array of care to chronically ill or disabled relatives or friends in the home
  - ▶ Can be wife, husband, daughter, son, grandchild, close friend, neighbor
  - ▶ Majority are women, primarily wives (Rabins, Lyketos, & Steele, 1999)
  - ▶ Spousal caregivers usually elderly & may have own medical conditions.
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# Who Are Family Caregivers? (Cont.)

- ▶ Provide 80% of chronic illness home care services to persons age 50 and above
- ▶ Provide daily care including
  - Medication management
  - Symptom management
  - Hands-on care
  - Emotional support
  - Davis, 1996; Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000)
- ▶ Are important and valuable to the care of the PD patient

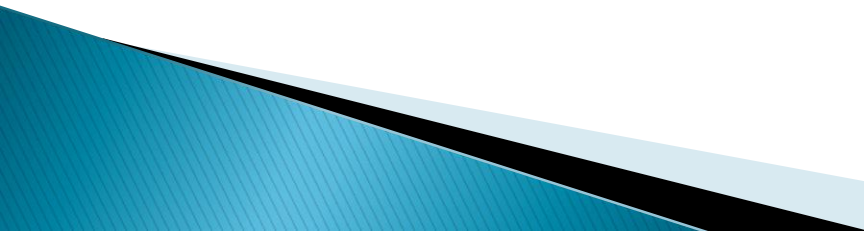
# Value of PD Family Caregivers

## ▶ To the Clinician

- Enhance communication between patient and clinician
  - Assist with adherence to medication and device regimes
  - Help organize and coordinate medical care
  - Provide a more objective reporting of symptoms
  - Remind and reinforce instructions
  - May be more reliable than patient
  - Can be the, “voice of reason”
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# Value of PD Family Caregivers (Cont.)

## ▶ To the Clinician

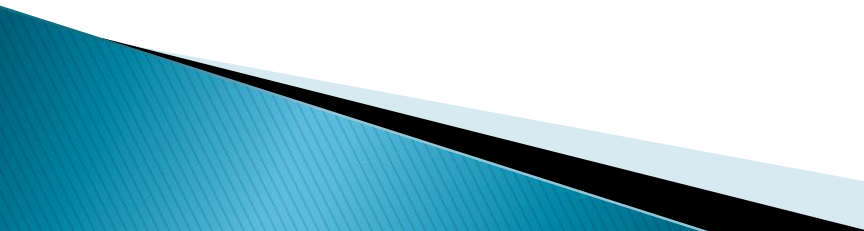
- “Caregivers are famously active online and keep track of so much of what's going on in the media (in support groups, chat rooms, and in the lay press, etc..).”
  - “They are often our “eyes and ears”, being the first person that makes us aware of the new hot topics that people are talking about...”
  - They help with transfers in the clinic
  - They are the, “Resource generator,” (find the help)
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# Clinicians & PD Caregiver

- ▶ Include PD caregiver in treatment plan, education & all aspects of patient's care
- ▶ Understand the caregiver role
- ▶ Help with caregiver issues



# Understanding the PD Family Caregiver Role

- ▶ Help with ADLs, medication management & administration, household chores, financial management, transportation, emotional support, medical plan management
  - ▶ Cope with nonmotor symptoms (Depression, anxiety, sleep disturbance, dysphagia, sexual dysfunction, etc.), can be more difficult than motor symptoms
  - ▶ Role is demanding, a 24-hour job 7 days per week & duties increase with advancement of disease
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# Stresses of PD Caregiving

- ▶ Caregivers often ill equipped to manage the emotional & physical demands of caregiving
- ▶ Face increasing demands due to PD progression
- ▶ Have their own aging processes & physical decline
- ▶ Caregiving can place constraints on
  - Social & family life
  - Employment & finances



# Caregiver Burden

- ▶ The degree of caregiver's awareness that their own health, socialization, & financial situation is being adversely affected due to caregiving obligations (Rabins et al., 1999).
- ▶ Research has shown family caregivers often experience:
  - Stress
  - Depression
  - Compromised physical and psychological health
  - Premature mortality
    - (Aranda, 1997; Bodnar & Kiecolt-Glaser, 1994; Mastrian, Ritter, & Deimling, 1996, Rose-Rego et al, 1998; Schulz & Beach, 1999)
  - Caregiver suicide has been reported

# How to help the PD Caregiver

- ▶ Be aware of caregiver needs
- ▶ Provide ongoing education & support to patient and caregiver
- ▶ Refer to:
  - Support Group for Caregivers
  - Mental Health Services/counseling
  - Social Services
    - Provide information on community services, financial information, and end of life care

# Encourage PD Caregiver To:

- ▶ Maintain their own health
  - Make & keep medical, dental appointments
- ▶ Take breaks (get-a-ways & mini-breaks)
- ▶ Get their sleep (even if PD person can't)
- ▶ Make & keep social & Spiritual
- ▶ Keep (or develop) sense of humor



# How to help the PD Caregiver



- ▶ Get help!
  - From family, neighbors, friends, church, synagogues
- ▶ Benefits
  - Lessen feelings of isolation
  - Helps get those needed breaks
  - Gives more confidence

# Advanced Parkinson's Caregiving



- ▶ Home Health & Respite care
- ▶ Care outside the home
- ▶ Hospice Care

# Home Health & Respite Care

## ▶ Home Health

### ◦ VA programs:

- Homemaker Home Health Aide
- Aid and Attendance & Housebound through VA Pension program

[www.vba.va.gov/bln/21/pension/vetpen.htm](http://www.vba.va.gov/bln/21/pension/vetpen.htm)

### ◦ Medicare

- Requires 3 day hospital qualifying stay
- RN, PT, OT, nurse aid services

## ▶ Respite

- Temporary care of patient in nursing home
- SFVA provides 12 days, twice/year, no cost
- Caregiver & patient both get needed break

# Care out of the home

- Difficult decision for both caregiver and PD patient
- Not a failure of caregiver
- Realization that care required is beyond what caregiver can provide
  - Caregiver can no longer:
    - Perform physical tasks, i.e., lifting, pulling, turning, incontinence care, protection from falling, etc.
    - Handle emotional problems, i.e., dementia, psychosis, sleep disturbance
- Caregiver remains caregiver but level & type changes
- Caregiver becomes patient advocate & overseer of care provided



# Options for care out of home

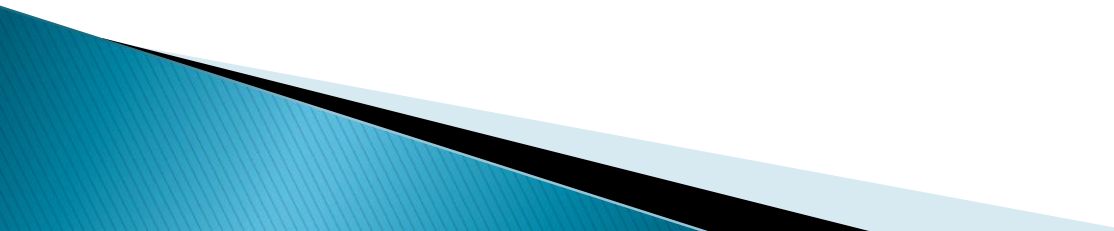


- ▶ Continuing Care Retirement Community
  - Covers all levels of care but expensive
- ▶ Assisted Living Facilities
- ▶ Board & Care--usually small, more personal
- ▶ Nursing homes

# Hospice Care

- ▶ Hospice: interdisciplinary group of skilled professionals trained to support the PD patient and their family through end-of-life care and bereavement services (Foley & Carver, 2001)
- ▶ Care provided in home, nursing home, assisted living, hospital
- ▶ Services paid for by Medicare Part A
  - VA will pay if patient doesn't have insurance
- ▶ MD must determine PD patient has 6 months or less to live—difficult for MD & caregiver
- ▶ Introduce idea before caregiver is too exhausted

# Local & Community Resources for Caregiver

- ▶ 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 (help with cooking, bathing, dressing, meal prep, etc.)
  - ▶ Social Worker from health plan or hospital
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# Online Resources

- ▶ 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

# The Results

