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 feedback 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’s 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 a sign of strength, not weakness
- Make a list of caregiver tasks in a typical week
- Organize the list into categories
  - Caregiver needs & how people can help
  - Decide what to let go & what to keep

Caregiving Tasks Example

<table>
<thead>
<tr>
<th>Caregivers Needs</th>
<th>How friends/family can help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ride to MD</td>
<td>Chauffeur Service date/time</td>
</tr>
<tr>
<td>Make dinner</td>
<td>Meal prepared &amp; delivered</td>
</tr>
<tr>
<td>Insurance company</td>
<td>Forms filled out &amp; advocate</td>
</tr>
<tr>
<td>Keep house clean</td>
<td>“Maid brigade”</td>
</tr>
<tr>
<td>Keep food in house</td>
<td>Grocery shopping per week</td>
</tr>
<tr>
<td>House maintenance</td>
<td>Handyman, kid to mow lawn</td>
</tr>
</tbody>
</table>
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
• National Family Caregivers Association
  - www.thefamilycaregiver.org
• American Parkinson’s Disease Association
  - www.apdaparkinson.org
• National Parkinson’s Association
  - www.parkinson.org
• Michael J. Fox Foundation
  - 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