Coping with Dementia for Care Partners

Joseph Quinn, MD
Professor of Neurology, School of Medicine
Director OHSU Parkinson Center and Movement Disorders Program School of Medicine
Director, Portland VAMC Parkinson’s Disease Research, Education and Clinical Center*

November 5, 2019
Zoom Video Communications was Named a 2018 Gartner Peer Insights Customers' Choice for Meeting Solutions!*

Zoom received a 4.69 out of 5 overall customer rating.
Poll #1: Who Are You?
Poll #2 True or False

True or False: Dementia is the same thing as Alzheimer’s disease.
Poll #3: True or False

True or False: Dementia is rare in Parkinson’s disease.
Poll #4: True or False

True or False: Dementia caregivers are at increased risk of poor health compared to their peers.
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Disclosures

none
Background: Definitions

Dementia
Mild cognitive impairment
Alzheimer’s disease
Parkinson’s disease dementia
Lewy body dementia
Background: Definitions

Dementia:
- Broad term for thinking impairments interfering with daily activities.

Mild cognitive impairment:
- Thinking impairment but no deficit in daily activities.

Alzheimer’s disease:
- Most common type of dementia, with memory impairment, “plaques”.

Parkinson’s disease dementia:
- Patient has “motor” symptoms of PD for many years, then cognitive decline.

Lewy body dementia:
- Patient has motor problems and cognitive problems from the beginning and they progress together.
Background

Cognitive impairment and dementia are common in Parkinson’s.

Parkinson’s dementia is different from Alzheimer’s dementia:
- more trouble with “multi-tasking” and planning
- more trouble with visual functions
- often associated with hallucinations

Caregivers of dementia patients are at risk of adverse effects on their own health.
Two lists

1) 10-point checklist for ensuring the best care of the patient with dementia.
2) 7-point checklist for maintaining the health of the care partner
Dementia caregiving: it takes a village

Doctors
Nurses
Lawyers
Social workers
Parkinson’s Foundation
Alzheimer’s Association
Dementia “Checklist for families”

#1: Be sure you have an accurate diagnosis.
#1: Be sure you have an accurate diagnosis.

– There are some treatable conditions that “look like” dementia.
– Ask for an evaluation by neurology, psychiatry, or geriatrics if the PCP is not up to completing a diagnostic evaluation.
– Beware that diagnosis is made “on clinical grounds” since there is no simple brain scan or blood test to make the diagnosis.
#2: Find a physician who is familiar with dementia.
#2: Find a physician who is familiar with dementia.

Doesn’t need to be a sub-specialist—just someone who is comfortable dealing with dementia symptoms and needs.
Dementia “Checklist for families”

#3: Get education on dementia.
Dementia “Checklist for families”

#3: Get education on dementia.

Medical – diagnosis, prognosis, treatment
Legal – Advanced directive, POA
Communication
Safety issues

The Parkinson’s Foundation has excellent educational material on cognitive change in Parkinson’s.

The Alzheimer’s Association is also a good resource—they serve all patients with memory disorders, regardless of diagnosis. They have a variety of educational material: written, on-line, DVDs, classes, etc. (www.alz.org)
Dementia “Checklist for families”

#2: Get education on dementia.

www.parkinson.org

• “PD library”
• Search on “cognition” or “dementia”
Dementia “Checklist for families”

#4: Plan a family meeting.
Dementia “Checklist for families”

#4: Plan a family meeting.-why?
– To make everyone aware of the patient’s evolving needs.
– To prepare for the future: more assistance, modified communication.
– To arrange support for the primary caregiver.
If you want to call a family meeting just turn off the WiFi router and wait in the room in which it's located.
#5: Include the person with dementia in the decision-making process.
Dementia “Checklist for families”

#5: Include the person with dementia in the decision-making process.

– Dementia patients vary in the amount of insight they have in the early stages.
– Personality and judgment are usually intact at the earliest stages of memory loss.
– It’s healthy for both the patient and primary caregiver to have the opportunity to express care preferences.
Dementia “Checklist for families”

#5: Include the person with dementia in the decision-making process.
Dementia “Checklist for families”

#6: Consider and monitor safety issues.
Dementia “Checklist for families”

#6: Consider and monitor safety issues—even in patients with early, mild dementia:

- 1) driving
- 2) guns
- 3) money
- 4) medication
Dementia “Checklist for families”

#6: Consider and monitor safety issues—even in patients with early, mild dementia:

– Medication:

  • **Know the patient’s medications!!**
  • Make a list of the medications and doses and confirm with the doctor.
  • If the patient is able and willing to play a role, a weekly pillbox can be used and the patient can take the meds, but it needs to be monitored regularly.
  • Patients with high-risk medications like insulin and coumadin need to be monitored even more closely.
Dementia “Checklist for families”

#7: Work out financial and legal issues.
Dementia “Checklist for families”

#7: Work out financial and legal issues.

– Everyone:
  • Advanced Directive, POA for health care, POA for finances
  • POLST in later stages

– Select instances:
  • Conservatorship, guardianship
#8: Provide an ID bracelet or tag.
Dementia “Checklist for families”

#9: Seek out support services.
Dementia “Checklist for families”

#10: Focus on the needs of the primary caregiver.
Dementia “Checklist for families”

#10: Focus on the needs of the primary caregiver.
– Prepare an emergency care plan
– Attend support groups
– Arrange for weekly personal time
– Be sure to get adequate sleep
– Develop humor to reduce stress
– Maintain friends who are understanding and supportive
– Value yourself as an individual
Checklist:

#1: Be sure you have an accurate diagnosis.
#2: Get education on dementia.
#3: Find a physician who is familiar with dementia.
#4: Plan a family meeting.
#5: Include the person with dementia in the decision-making process.
#6: Work out financial and legal issues.
#7: Consider and monitor safety issues.
#8: Provide an ID bracelet or tag.
#9: Seek out support services.
#10: Focus on the needs of the primary caregiver.
#10: Focus on the needs of the primary caregiver.

- Are there concrete recommendations for heart and brain health maintenance that might be used as a roadmap?
  
  - Measurable, specific targets
  - Supported by solid science, vetted by medical experts
  - “Action-able”: things you can improve with specific actions
“All the things that we know are bad for your heart turn out to be bad for your brain.”

Marilyn S. Albert, PhD
Johns Hopkins Medical Institutions
American Heart / Stroke Association
- Aerobic exercise
- Control cholesterol
- Eat according to AHA guidelines
- Manage blood pressure
- Lose weight
- Reduce blood sugar
- Stop smoking
American Heart / Stroke Association

- Aerobic exercise
- Control cholesterol
- Eat according to AHA guidelines
- Manage blood pressure
- Lose weight
- Reduce blood sugar
- Stop smoking

Only 2% of the American population meets all 7 guidelines.
(www.AHA.org)
Need a doctor’s help for some:
- Aerobic exercise
- Control cholesterol**
- Eat according to AHA guidelines
- Manage blood pressure**
- Lose weight
- Reduce blood sugar**
- Stop smoking
But many can be done on your own:

- Aerobic exercise**
- Control cholesterol
- Eat according to AHA guidelines**
- Manage blood pressure
- Lose weight**
- Reduce blood sugar
- Stop smoking**
Heart Health Factors

Get Active

**Why Get Active?**
We all know that exercise is good for us, but nearly 70% of Americans do not get the physical activity they need. Living an active life is one of the most rewarding gifts you can give yourself and those you love. Simply put, daily physical activity increases your length and quality of life. If you get at least 30 minutes of moderate physical activity each day (like brisk walking), five times per week, you can almost guarantee yourself a healthier and more satisfying life while lowering your risks for heart disease, stroke and diabetes. Parents, your children need 60 minutes a day—every day—so when you get active, you’re also modeling healthy living for the next generation.

**The Price of Inactivity**
If you exercise less than 150 minutes per week, you need to increase your activity level. Regular moderate intensity physical activity helps keep your heart in good condition. When you are inactive, you burn fewer calories, you are at higher risk for cholesterol problems, blood sugar and blood pressure problems, and your weight is often harder to manage. If that’s not enough, physically active people nearly always report better moods, less stress, more energy and a better outlook on life.

**What Can I Do To Get Active?**
- **Make the time**
  Nearly all of us feel time-crunched and over-scheduled. And although anyone can fall into a busyness trap, only you can make your health a priority over life’s other demands. Even our nation’s President sets aside time to exercise. It can be done and only you can say ‘no’ to interruptions and ‘yes’ to your good health!
- **Start with walking**
  Walking is one of the best ways to get started. It’s easy, it’s social, it requires no special equipment, and it works! Just walk fast enough to get your heart rate up. Most of us can expect to cover 2 miles or more in a thirty minute block of time. If thirty minutes seems like an impossible goal, start with less. Some physical activity is always better than none! You can chart your progress as you work your way toward your goals.
Get Moving!
You'll feel better and your health depends on it!
By exercising for as little as 30 minutes a day you can reduce your risk of heart disease. In fact, studies show that for every hour of walking, you may increase your life expectancy by two hours. The time to get moving is now! Start with a small goal and commit to it regularly. It won't be long before you're enjoying the benefits of an active life.

Learn More →

The Price of Inactivity
As adult and childhood obesity levels rise, so does the impact on our nation's health.

American Heart Association Recommendations
Read the American Heart Association Recommendations for Physical Activity.
Sample “Life’s Simple 7” scorecard:

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<th>target</th>
<th>status</th>
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<td>Smoking</td>
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<td>no</td>
</tr>
<tr>
<td>Hypertension</td>
<td>&lt;120/80</td>
<td>140/90</td>
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<tr>
<td>Diabetes ( fasting glucose)</td>
<td>&lt;100</td>
<td>??</td>
</tr>
<tr>
<td>Cholesterol</td>
<td>&lt;200 mg/dl</td>
<td>??</td>
</tr>
<tr>
<td>Diet</td>
<td>4/5 AHA guidelines*</td>
<td>Not meeting</td>
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<tr>
<td>Physical exercise</td>
<td>150 minutes per week</td>
<td>100-150 minutes per week</td>
</tr>
<tr>
<td>Body mass index</td>
<td>&lt;25</td>
<td>27.2</td>
</tr>
</tbody>
</table>
Take home message

10 point checklist for optimizing care for the patient.

7 point checklist for optimizing the health of the caregiver.
Poll #5: True or False

True or False: Dementia is the same thing as Alzheimer’s disease.
Poll #6: True or False

True or False: Dementia is rare in Parkinson’s disease
Poll #7: True or False

True or False: Dementia caregivers are at increased risk of poor health compared to their peers.
Poll #8: Checklist

Poll: What information will you use in your approach as a care partner?
More than 60,000 individuals are diagnosed with PD every year. Close to 50% of them leave their diagnosing physician without resources or information on what the future holds. The Parkinson’s Foundation announced the Newly Diagnosed Initiative to close this gap and provide ongoing support.

Get connected and your questions answered today:

**Visit:** Parkinson.org/NewlyDiagnosed

**Call:** 1.800.4PD.INFO (473.4636)

**Email:** NewlyDiagnosed@Parkinson.org
Alumni of ATTP are added to our *National Helpline Referral List* of trained health professionals.
Resources

National Helpline
Specialists answer calls about all aspects of Parkinson’s in addition to helping you locate your local PD trained allied health professional therapist.
1-800-4PD-INFO
Helpline@Parkinson.org
Mon- Friday 9 am to 8 pm ET

Fact Sheets and Publications
Get the resources and information you need to start living a better life with Parkinson’s.

Podcast: Substantial Matters
New episodes every other Tuesday featuring Parkinson’s experts highlighting treatments, techniques and research.
Parkinson.org/Podcast

Aware in Care Kit
Includes tools and information for people with PD to share with hospital staff during a planned or emergency hospital stay.
Parkinson.org/Awareincare