

Dementia Care During COVID-19: Lessons from Patients and Recommendations for Providers

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Today's Road Map

- COVID-19 and older adults (WA facts and figures)
- COVID-19 and Dementia – What we know
- Findings from COVID-19 qualitative study in WA state
- Practical Recommendations for Providers and Caregivers
- Additional Resources

What You Can do if You are at Higher Risk of Severe Illness from COVID-19

(Print Resources Web Page: <https://www.cdc.gov/coronavirus/2019-nCoV/communication/print-resources.html>)

Are You at Higher Risk for Severe Illness?



Based on what we know now, those at high-risk for severe illness from COVID-19 are:

- People aged 65 years and older
- People who live in a nursing home or long-term care facility

People of all ages with underlying medical conditions, particularly if not well controlled, including:

- People with chronic lung disease or moderate to severe asthma
- People who have serious heart conditions
- People who are immunocompromised
 - Many conditions can cause a person to be immunocompromised, including cancer treatment, smoking, bone marrow or organ transplantation, immune deficiencies, poorly controlled HIV or AIDS, and prolonged use of corticosteroids and other immune weakening medications.
- People with severe obesity (body mass index (BMI) of 40 or higher)
- People with diabetes
- People with chronic kidney disease undergoing dialysis
- People with liver disease

Here's What You Can do to Help Protect Yourself



Stay home if possible.



Wash your hands often.



Avoid close contact (6 feet, which is about two arm lengths) with people who are sick.



Clean and disinfect frequently touched surfaces.



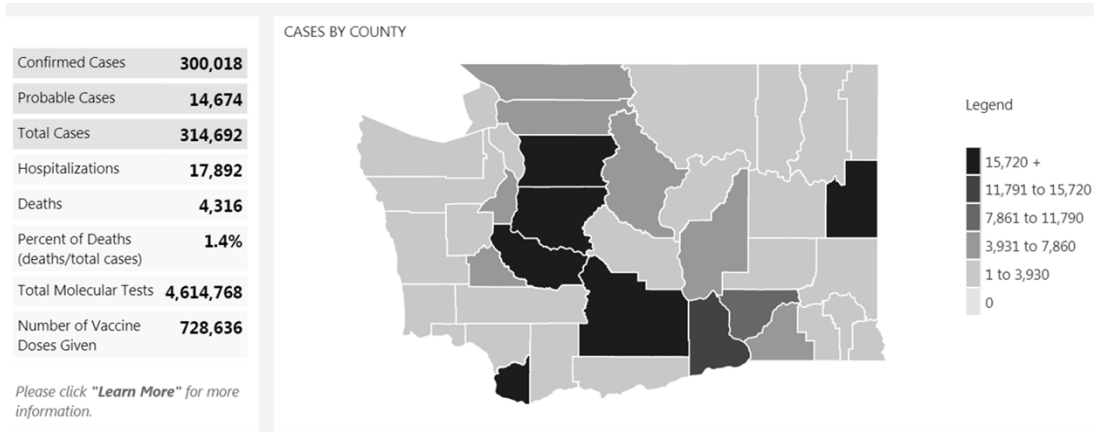
Avoid all cruise travel and non-essential air travel.

Call your healthcare professional if you are sick.
For more information on steps you can take to protect yourself, see CDC's How to Protect Yourself.

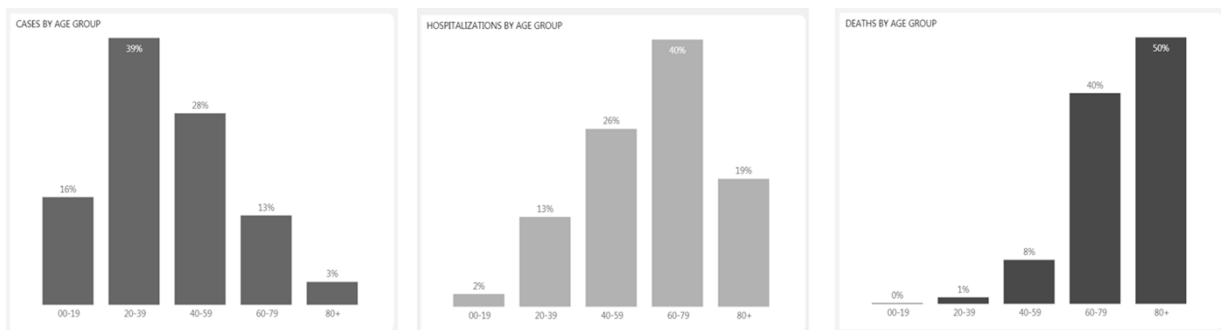


cdc.gov/coronavirus

COVID-19 Facts & Figures (WA DOH, 2/1/2021)



COVID-19 Demographics (WA DOH, 2/1/2021)



- Older adults are experiencing worse outcomes and higher mortality
- Age 60+ make up 60% of COVID-related hospitalizations and 90% of COVID-related deaths in WA

<https://www.doh.wa.gov/Emergencies/NovelCoronavirusOutbreak2020COVID19/DataDashboard>

COVID-19 and Dementia: What Do We Know?

- All PRELIMINARY FINDINGS at this time. Research is ongoing
- SARS-CoV-2 has been associated with neuropsychiatric symptom sequelae
 - Impacts on the CNS system, causing headaches, reduced taste and smell, ataxia, AMS and delirium
 - Independent of multi-organ failure
 - Increased stroke risk
 - Higher long-term risk for cognitive decline or dementia
 - Encephalopathy
- Increased risk of neuropsychiatric sequelae in specific populations
 - Comorbid conditions: diabetes, smoking, obesity
 - Black/African American and LatinX communities > Non-Hispanic White
 - Even after correcting for other SES and medical factors

COVID-19 and Dementia: What Do We Know?

- Early studies estimate 10-30% of ICU discharge for COVID-19 showed some degree of cognitive symptoms (Rogers et al., 2020; *Lancet Psychiatry*)
- Coronaviruses (in general) can cause demyelination and neurodegeneration
 - Associated with pro-inflammatory cytokines, acute respiratory distress, hypoxia
- Whether this will occur in COVID-19 recoverees remains to be seen

COVID-19 and Dementia: What Do We Know?

- Longitudinal and biomarker studies are underway
 - Alzheimer's Association/WHO: https://www.alz.org/research/for_researchers/partnerships/sars-cov2-global-brain-study
 - NeuroCOVID Biobank: <https://med.nyu.edu/departments-institutes/population-health/divisions-sections-centers/biostatistics/research/nih-neurodatbank-neurobiobank>

COVID-19 and Dementia in Washington State

Link to full report:
<https://authors.elsevier.com/a/1cIDs5QyCq5vbr>

W **CARING FOR WASHINGTON'S OLDER ADULTS IN THE COVID-19 PANDEMIC: INTERVIEWS WITH ORGANIZATION LEADERS ABOUT THE STATE OF SOCIAL AND HEALTHCARE SERVICES**



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UW Population Health Initiative: COVID-19 Economic Recovery Grant



- Qualitative study
- 5 months: July-November 2020
- “Intended for rapid response to the economic challenges the pandemic has created”
- Focus on impacts on aging and dementia care services in Washington state

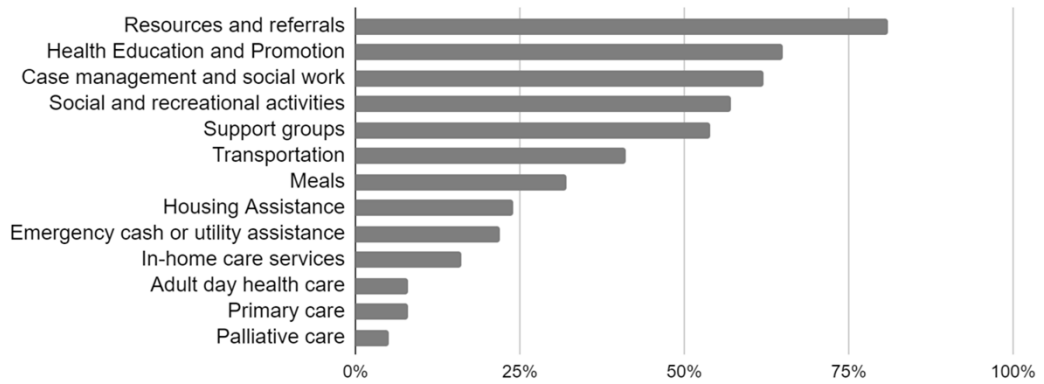
Qualitative Study – Summer 2020

- Data collection: July 14 – August 27, 2020
- Online survey of clients served
- One-on-one interviews via Zoom
- Convenience and snowball sampling
- 45 organizations
 - Social services: Area Agencies on Aging, senior centers, adult day health centers, nutrition and transportation services
 - Healthcare: memory clinics, geriatricians, palliative and hospice care

Healthcare and Social Service Organizations Interviewed by Region



Percent of Organizations Providing Services



Social Isolation

- “They’re more withdrawn, less motor active, less engaged despite encouragement because they’re kept in their rooms a lot. They’re getting more so.”
- “...the families are not allowed to go in, and I would get calls from the family members that they would see their family members less engaged, less verbal output, more agitation or more behavioral changes, more falling, and weight loss.”

Declines in Physical Functioning and Higher Use of ED

- “I’ve seen a great deal of the conditioning, progression of their dementia. A lot of emergency visits. They’ve been falling, and I think it’s social isolation that they also experience. They’re losing weight. They’re not being able to monitor how the intake of the residents are doing. I’ve seen dehydration, visits to the emergency room. It’s very common now.”

Declines in Cognitive Functioning and Increased Behavioral Symptoms

- “We’re definitely seeing more – more loss of cognitive skills as the – as this pandemic is going on longer.”
- “The ones that had a little bit of paranoia beforehand about, “Someone stealing from me, this is missing from my room, I’m sure that so-and-so, the house cleaner, took my hearing aid,” that’s getting amplified, mostly because they’re not getting out. And that room becomes their space.”

Increased Behavioral Symptoms and Limited Non-Pharmacological Options

- “Usually...we try all these non-pharmacological approaches to address them because that's really the – kind of the fastest and safest way. But a lot of those are not an option right now, and so we're turning more to medications which I kind of hate to deal with. We're kind of stuck with that right now, so I'm finding myself prescribing more antidepressants and antipsychotics, not just because I don't have the other piece to be able to intervene.”

Delaying Care

- “...a lot of folks who would access services are putting them off... The doctor suggested I go see a specialist for whatever, I'll do it when COVID's over. Which is scary because you never know what else is underlying all that...They're waiting, which is not good.”

Difficult Decisions when Seeking Care

- “There's a lot of decision issues in elderly people who have limited decisional capacity or they need help with some of that decision making... the tension between those decisions have ramped up. ‘Well, if I go into the hospital, I may never see my loved one,’ and they may die and that's it. That's a really hard thing to face. But if I keep them home, they might not get the care they need in a home setting.”

Need for Better Communication

- “The husband was actually at [a skilled nursing facility] when this was all starting, and he got infected and then taken to a hospital...the wife did not know what was going on. No one was telling her what to do until our case manager called in to check in and see how she was doing and said, ‘Oh, I’m so glad you called me. I haven’t heard anything from anybody. I don’t know what’s happening to my husband’...”

Preserving the Humanity in Telemedicine

- “With hospice I had to FaceTime a guy twice...he has ALS and he's dependent on a ventilator that he wears all the time... the discussion was around under what conditions and when would he take the mask off and die relatively quickly. That, it worked, it was okay, but having that kind of conversation on a video versus being in person, I didn't like personally. It just felt, not being physically present, it was a little unsettling”
- “It didn't feel like I was giving him my full presence, my full attention for something like that.”

Preserving the Humanity in Telemedicine

- Outpatient, non-urgent clinics
 - Good for check-ins, allowing family members to join
 - Using how-to options prior to calls
 - Defaulting to simpler apps, like Doximity or one-click Zoom
 - Difficult for non-English speaking and complexity of an interpreter with cross-talk

Promising Practices & Creative Adaptations

- Wellness checks, phone calls, newsletters
- Drive-through social events
- Forming pods for limited social contact in residences
- Outdoor distanced picnics, gardening, book tables
- Collaborations with local grocers/farmers for delivery meals and pantry items

Promising Practices & Creative Adaptations

- Moving Services Online
 - Telemedicine and the need for ongoing Medicare billing support
 - Online or phone support groups for patients and caregivers
 - Activity-based social groups on video-conferencing platforms



Practical Recommendations for Providers

Communicating Change

- Major changes in routine can increase mood and behavioral symptoms
 - Establish a new routine at home with a daily schedule
 - Alz Association “Daily Care Plan”
<https://www.alz.org/help-support/caregiving/daily-care/daily-care-plan>
- Simplify. Give only the amount of information needed
 - Consider limiting news (e.g., once per day) to minimize stress
- Roll with Resistance (key principle of MI)
- “Use What the Dementia Gives”
- Supportive statements
 - “We’re doing everything we can to stay healthy”
 - “This is how we stay safe right now”

alzheimer's  association®

Daily plan example (for early- to middle-stages of the disease)

Morning

- Wash, brush teeth, get dressed
- Prepare and eat breakfast
- Have a conversation over coffee
- Discuss the newspaper, try a craft project, reminisce about old photos
- Take a break, have some quiet time
- Do some chores together
- Take a walk, play an active game

Afternoon

- Prepare and eat lunch, read mail, wash dishes
- Listen to music, do crossword puzzles, watch TV
- Do some gardening, take a walk, visit a friend
- Take a short break or nap

Evening

- Prepare and eat dinner, clean up the kitchen
- Reminisce over coffee and dessert
- Play cards, watch a movie, give a massage
- Take a bath, get ready for bed, read a book

Hygiene and Handwashing

- Extra reminders for hygiene (e.g., note on the bathroom mirror)
- Regular hand washing practice (e.g., every hour we wash our hands)
 - Sanitizer as an option when not near a sink or difficulties with mobility (>60% alcohol)
- Illusion of choice
 - “Would you like to wash your hands with soap or use sanitizer?”
- Use other hygiene activities to mimic handwashing (e.g., washing dishes in a sink full of soapy water). Include cleaning activities as part of daily routine.



Preserving the Humanity in Telemedicine

- Take a few extra minutes for orientation and introductions
- Treat a video visit like an in-person visit
- Turn the camera on whenever possible
 - If you can, remove your mask to allow for visual cues
 - Look into the camera, not down at your screen
- Speak clearly and allow for pauses. Avoid crosstalk.
- Use a headset to avoid background noise

Masks

- Masks remain necessary, even if patients and staff have been vaccinated
- Per CDC guidelines (2/2021; [cdc.gov](https://www.cdc.gov))
 - Masks should not be placed on anyone who has trouble breathing or is incapacitated (or unable to remove the mask without assistance)
 - A mask is not a substitute for social distancing
- Reminders for masks in public places. If mask refusal, continue to stay at least 6 feet from others.
 - Signage for LTC facilities available through CDC website



Care for Chronic Conditions and New Problems

- Encourage regular follow-up for chronic conditions to avoid problems later
 - Diabetes, hypertension, hyperlipidemia, COPD, sleep apnea, hearing loss, etc
- Consider options for telemedicine
 - Assist patients and families with visit set-up ahead (instructions, resources for the family)
- If patients are coming into the clinic, provide reminders for masks, hand sanitizing or hand washing
 - Avoid gathering in areas if possible (e.g., cafeteria, crowded waiting room)

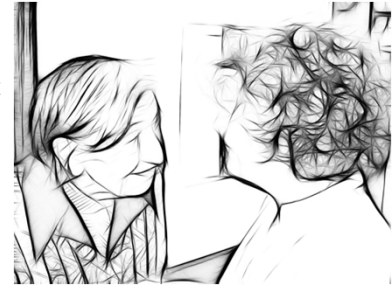
Staying Connected During Social Distancing

- Establish a routine for socializing
- Phone and Video calls: Skype, Zoom, FaceTime
- Writing letters, poems, or short stories
- “Lawn conversations”
- Online Groups & Apps
 - Music: The Sofa Singers
 - Exercise: Silver Sneakers
 - Videos: Watch2Gether, NetflixParty
 - Games: HouseParty



Caring for the Care Partners

- Self-care practices and respite, planned into daily routine
 - Mindfulness-based relaxation, exercise, journaling
 - Before PWD wakes up, during a nap, or after they go to bed at night
- 5-minute distractors or tasks to give self a break or chance to “reset”
 - Sorting papers, washing dishes, vacuuming
- Consider risks and benefits of home-based care
 - Home care providers are exposed to others, mask requirements, etc
 - Contact the home health care provider and ask them to explain their protocols
 - Temperature checks, exposure to anyone who has tested positive
 - Hand washing and mask protocol



Long-Term Care Facilities & Visitations

- Have a contingency plan
 - “What You Should Know” fact sheets for each PLWD
 - Preferred name, names of family/friends, cultural background, hobbies and interests, religious or spiritual preferences
 - Typical behavior patterns; what upsets the person and what helps
 - Strengths and capabilities (which communication methods are effective)
 - Advanced Care plans and any directives on file for each PLWD
 - CDC has a printable [checklist](#) for LTC facilities for responding to COVID-19
- Keep friends and family informed
 - Changes in policies or procedures, visiting hours or limitations
 - “Phone tree”, e-mail listserv, or social media

Long-Term Care Facilities & Visitations

- Walking and Moving about the LTC facility
 - Provide safe spaces for walking and exercise
 - Structured activities during the day, for physical activity and routine
 - Outdoors time when possible
- Management of behaviors
 - Proactive is better than reactive
 - Encourage routine and consistency
 - Calm environment, management of stimulation
 - Person-centered care and information sharing

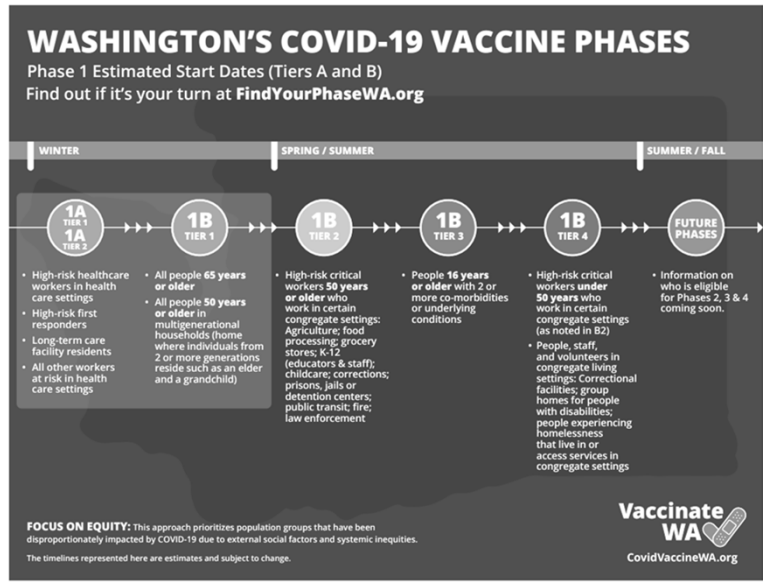


Vaccines (as of 2/2/2021)

- People with dementia and their caregivers are encouraged to get the COVID-19 vaccine, pending no other contraindications
 - PLWD are usually older adults and at higher risk for serious complications of COVID-19
 - Family caregivers cannot provide proper care to their loved one if their own health is compromised
- "Getting vaccinated is one of the most important steps families affected by Alzheimer's disease can take to protect themselves and their loved ones" - Dr. J. Wesson Ashford, chair of AFA

Vaccines (as of 2/2/2021)

- Current vaccine roll-out is state-based
 - PLWD in LTC/ALF settings are included in Phase 1A
 - WA is presently in Phase 1B – Tier 1:
 - People 65yo+
 - People 50yo+ in multigenerational households
 - Phase 1B – Tier 2 is next:
 - High-risk critical workers 50yo+
- Vaccines are not a replacement for social distancing, hygiene, etc.
- www.doh.wa.gov
- www.alz.org/alzheimers-dementia/coronavirus-covid-19-vaccine



Resources for COVID-19 in Dementia

- CDC Resources
 - www.cdc.gov/COVID-19
 - www.cdc.gov/coronavirus/2019-ncov/community/retirement/index.html
 - www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/caregivers-dementia.html
- Alzheimer's Association Resources
 - www.alz.org/alzheimers-dementia/coronavirus-covid-19
 - www.alz.org/professionals/professional-providers/coronavirus-covid-19-tips-for-dementia-caregivers
 - www.alz.org/media/Documents/COVID-19-EmergencyTips_LongTermCommunityBasedDementiaCare_AlzheimersAssociation.pdf

Virtual Resources from UW MBWC

<http://depts.washington.edu/mbwc/events/community-events-programs>

Virtual Support, Education & Engagement during the time of COVID-19

Virtual Coffee Chats for persons with memory loss/dementia

Make a cup of coffee or tea, and come together for an informal social time with others living with memory loss or dementia. Share how you're coping in the midst of COVID-19, and reflect on a different theme each week. Participate online or by phone, with a free application called "Zoom." Facilitated by program manager Marigrace Becker. Join for just one session, or multiple. Space is limited; sign up by the day before.

Tuesday, June 2, 10 - 11 a.m.

Tuesday, June 9, 10 - 11 a.m.

Tuesday, June 16, 10 - 11 a.m.

Tuesday, June 23, 10 - 11 a.m.

Tuesday, June 30, 10 - 11 a.m.

[Sign Up Here](#)

Virtual Caregiver Forums

Join other family caregivers to discuss caring for a loved one in this time of COVID-19. Make meaningful connections, offer mutual support, and discover strategies that work for others. Participate online or by phone, with a free application called "Zoom." Facilitated by clinic social worker Karen Clay and program manager Marigrace Becker. Space is limited to 20 participants; sign up by the day before. Join for just one session, or multiple. Session themes are below.

10 a.m. Monday, June 1: Supporting a Loved One at Home

10 a.m. Monday, June 8: Supporting a Loved One in a Memory Care Facility

Virtual Resources from UW MBWC

<http://depts.washington.edu/mbwc/events/community-events-programs>

Virtual Community Wellness Talks

Join us for a brief presentation and Q&A from 1 - 1:45 p.m. on Wednesdays in June, on various topics related to "living well" in the midst of the COVID-19 outbreak. These talks are for people with memory loss, family caregivers, and the general public, and feature MBWC providers and university colleagues. Participate online or by phone, with a free application called "Zoom." Join for just one session, or multiple. Sign up by the day before. Session topics are below.

Wednesday, June 3: "Resilience Never Rests: Support During COVID-19" with Katie Brandt, Director of Caregiver Support Services and Public Relations for the Frontotemporal Disorders Unit at Massachusetts General Hospital. [View Recording.](#)

Wednesday, June 10: "Calming the Monkey Mind: an Introduction to Mindfulness-Based Stress Reduction" with neuropsychologist Dr. Emily Trittschuh, Geriatric Research and Education Clinical Center (GRECC) at VA Puget Sound; University of Washington School of Medicine, Department of Psychiatry. [View PowerPoint.](#)

Wednesday, June 17: "Caregiver Self-Care" with Dr. Tatiana Sadak, University of Washington School of Nursing.

Wednesday, June 24: "Grief and Loss along the Dementia Journey" with social worker Karen Clay, MSW.

Archived Recordings/PowerPoints of Previous Talks:

4/3: "Dementia Caregiving in the Midst of Covid-19 - Health, Safety and Communication" with ARNP Elisabeth Lindley. [View PowerPoint and Recording.](#)

4/8: "Staying Connected During Social Distancing" with neuropsychologist Carolyn Parsey, PhD. [View PowerPoint.](#)

4/10: Home Workouts 101 - "Staying Active with or without a Home Gym" with neuropsychologist Carolyn Parsey, PhD. [View PowerPoint.](#)

4/15: "Strategies for Stress Management" with neuropsychologist Kristoffer Rhoads, PhD. [View PowerPoint and Recording.](#)

4/17: "Info-Savvy - Staying Sane in the Era of Information Overload" with neuropsychologist Carolyn Parsey, PhD. [View PowerPoint.](#)

4/22: "Mind over Matter - Cognitively-stimulating activities for everyone" with neuropsychologist Carolyn Parsey, PhD. [View PowerPoint and Recording.](#)

4/24: "A Reason to Get Out of Bed in the Morning: Finding Purpose during COVID-19" with Program Manager Marigrace Becker, MSW. [View PowerPoint and Recording.](#)

4/29: "Enjoying the Arts from Home" with geriatrician Lee Burnside, MD. [View PowerPoint and Recording.](#)

5/1: "Virtual Nature for the Soul" with neuropsychologist Carolyn Parsey, PhD. [View PowerPoint and Recording.](#)

5/6: "Food for Thought: Brain-Healthy Meals" with geriatrician Angela Hanson, MD. [View PowerPoint and Recording.](#)

5/13: "Living with Dementia and Dementia Caregiving during COVID-19: An Update" with Elisabeth Lindley, ARNP. [View PowerPoint and Recording.](#)

5/20: "Practicing Self-Compassion" with neurologist Nancy Isenberg, MD, Medical Director for Center for Healthy Aging, Swedish Neuroscience Institute; Clinical Associate Professor of Neurology, University of Washington. [View Handout.](#)

5/27: "Sleep: Important considerations in the era of COVID-19" with neuropsychologists Dr. Pamela Dean and Dr. Madison Bertolin, VA Puget Sound. [View PowerPoint.](#)

Additional Resources

- **Alzheimer's Association Caregiving & COVID Free Webinar Series**
 - <https://alzwblog.org/covidcare/>
 - Legal Considerations, Self-Care for Caregivers, Coping with Loss, LTC Facilities
- **Alzheimer's Association COVID-19 website:** <https://alz.org/alzheimers-dementia/coronavirus-covid-19>
- **Alzheimer's Association 24/7 Helpline: 1-800-272-3900**
 - Staffed by counselors and social workers to help your patients and their caregivers with questions and local support resources
- **The AFTD – COVID 19 Resources:** <https://www.theaftd.org/living-with-ftd/covid-19-and-ftd/>
- **Lewy Body Dementia Association:** <https://www.lbda.org/Coronavirus>
- **Teepa Snow:** www.teepasnow.com (recent video: <https://www.youtube.com/watch?v=t9e2AB6Yw1s>)

Thank you!

UW Medicine – Department of Neurology
Memory and Brain Wellness Center at Harborview
<http://depts.washington.edu/mbwc/>

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