

## Disclosures

---

- No financial disclosures

## Objectives

---

- Describe the prognoses of different types of Dementia.
- Identify the horizon to benefit of common prevention plans.
- Discuss the advantages of patient-centered approaches to the care of individuals with Dementia.

## Case

---

74 y/o gentleman with history of HTN, HLD, BPH, COPD and recent diagnosis of probable Alzheimer's Dementia (MOCA 18/30) presents to initiate care in your Geriatrics clinic.

- He has lived with his wife in a 2-story home for 30 years.
- He is independent in his ADLs but for the last year has required assistance with finances and has limited himself to "local" driving. He has had a couple falls this year and "furniture surfs" but won't use any assistive devices.
- He has a history of smoking but stopped approximately 10 years ago.
- He has no currently documented Advanced Directives or Goals of Care
- His wife notes he is due for his colonoscopy and annual prostate specific antigen (PSA) test.

# Concept: Prognosis

---

- Forecast of the likely course of a disease
- A good tool to look at prognosis for patients in general (not Dementia specific):
  - \* <https://eprognosis.ucsf.edu/>

# Concept: Prognosis in the next year

---

**ePrognosis**      HOME   ABOUT   CALCULATORS ▾   CANCER SCREENING   DECISION AIDS   COMMUNICATION

---

**Gagne Index**

- Population: Community-dwelling adults aged 65 years and older
- Outcome: All cause 1 year mortality
- Scroll to the bottom for more detailed information

**Risk Calculator**

Has your patient been diagnosed with any of the following:

Metastatic cancer?	<input type="radio"/> Yes
	<input checked="" type="radio"/> No
Congestive heart failure?	<input type="radio"/> Yes
	<input checked="" type="radio"/> No
Dementia?	<input type="radio"/> Yes
	<input checked="" type="radio"/> No

### One Year Mortality

	Risk of ONE YEAR mortality (95% CI)
	2.4% (2.2-2.6)
	3.6% (3.4-3.8)
	5.1% (4.9-5.4)
	7.8% (7.4-8.3)
	11.3% (10.7-12.0)
	14.6% (13.8-15.5)
	20.1% (18.9-21.4)
	24.9% (23.3-26.5)
	29.5% (27.4-31.6)

# One-year mortality for our case

## Concept: Prognosis Over Time

ePrognosis

HOME ABOUT CALCULATORS ▼ CANCER SCREENING DECISION AIDS COMMUNICATION

### Lee Schonberg Index

- Population: Community dwelling adults aged 50 and older
- Outcome: All cause 4, 5, 10 and 14 year mortality
- Scroll to the bottom for more detailed information

#### Risk Calculator

1. How old is your patient?

Select ▼

2. What is the sex of your patient?

☐ Female

☐ Male

3. What is your patient's BMI?

Select ▼

## Concept: Prognosis Over Time

12. Because of a physical, mental or emotional problem, does your patient need the help of others in handling routine needs such as everyday household chores, doing necessary business, shopping, or getting around for other purposes?

☒ Yes

☐ No

13. Because of a health or memory problem, does your patient have difficulty managing money - such as paying bills and keeping track of expenses?

☒ Yes

☐ No

14. Because of a health or memory problem, does your patient have difficulty with bathing or showering?

☐ Yes

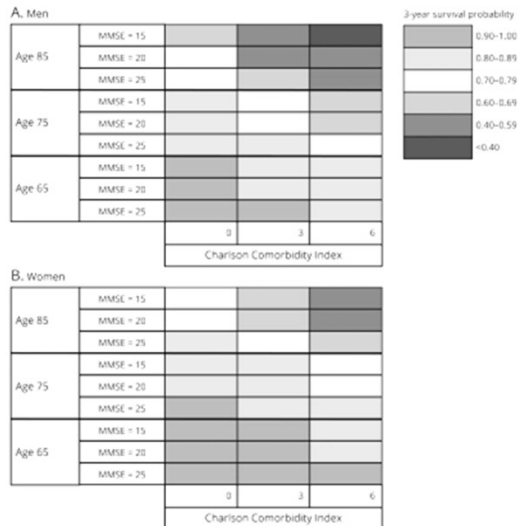
☒ No

## 5, 10- and 14-year mortality rates for our patient

Mortality Risk for Schonberg Index

Points	Risk of FIVE YEAR mortality	Risk of TEN YEAR mortality	Risk of FOURTEEN YEAR mortality
0 - 1	<3%	5 - 11%	19 - 21%
2 - 3	3 - 6%	9 - 12%	19 - 24%
4 - 5	7 - 8%	15 - 21%	27 - 36%
6 - 7	10 - 12%	26 - 37%	42 - 52%
8 - 9	17 - 27%	37 - 44%	42 - 52%
10 - 11	26 - 29%	53 - 60	74 - 78%
12 - 13	37 - 41%	60 - 68	81 - 83%

Figure 2 Three-year survival probabilities for (A) men and (B) women with dementia diagnosed in primary care



## Dementia Specific Prognosis

Haaksma ML, Eriksdotter M, Rizzuto D, Leoutsakos JS, Olde Rikkert MGM, Melis RJF, Garcia-Ptacek S. Survival time tool to guide care planning in people with dementia. *Neurology*. 2020 Feb 4;94(5):e538-e548

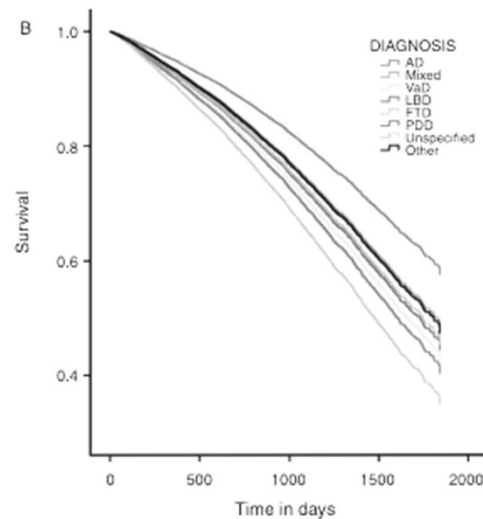
## Prognosis by Dementia Sub-type

- Complex and influenced by age, co-morbidities, dementia severity at the time of diagnosis and many confounders (race, socioeconomic status, etc.).
- 5-8 years on average from time of diagnosis to death, for late onset (after age 65) Dementia.
- There is some evidence that those with Vascular Dementia survive for a shorter time (likely due to risk of death by cardiovascular disease).

<https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf>, <https://www.alzheimers.org.uk/>, <https://www.ninds.nih.gov/>

## Prognosis by Dementia Sub-type

- A recent large (n~15,000) Swedish cohort study adjusted for age, gender, MMSE score, residential setting and number of medications at time of dementia work-up. Comparing survival time (days) they found Frontotemporal Dementia (FTD) had a faster rate of death than the other dementia sub-types.



GARCIA-PTACEK S, FARAHMAND B, KAREHOLT L, RELIGA D, CUADRADO ML, ERIKSDOTTER M (2014) MORTALITY RISK AFTER DEMENTIA DIAGNOSIS BY DEMENTIA TYPE AND UNDERLYING FACTORS: A COHORT OF 15,209 PATIENTS BASED ON THE SWEDISH DEMENTIA REGISTRY. J ALZHEIMERS DIS 41:467-477

## Concept: Horizon To Benefit

- Length of time needed to gain a clinically meaningful risk reduction for a specific outcome.
- Examples:
  - SSRI and “weeks” for depression
  - Anti-platelet medication and “same day” for acute myocardial infarction.

GUIDING PRINCIPLES FOR THE CARE OF OLDER ADULTS WITH MULTIMORBIDITY: AN APPROACH FOR CLINICIANS. GUIDING PRINCIPLES FOR THE CARE OF OLDER ADULTS WITH MULTIMORBIDITY: AN APPROACH FOR CLINICIANS. AMERICAN GERIATRICS SOCIETY EXPERT PANEL ON THE CARE OF OLDER ADULTS WITH MULTIMORBIDITY. J AM GERIATR SOC. 2012;60(10):E1-E25. DOI:10.1111/J.1532-5415.2012.04188.X



## Concept: Patient Centered Care

---

[HTTP://WWW.IHL.ORG/ENGAGE/INITIATIVES/AGE-FRIENDLY-HEALTH-SYSTEMS/DOCUMENTS/IHIAFRIENDLYHEALTHSYSTEMS\\_GUIDETOUSING4MSCARE.PDF](http://www.ihl.org/engage/initiatives/age-friendly-health-systems/documents/ihiafriendlyhealthsystems_guidetousing4mscare.pdf)

## Concept: Prevention

---

**Primary Prevention:** Goal is to prevent getting a disease (e.g.: vaccination)

**Secondary Prevention:** Goal is to detect a disease early to prevent it from getting worse (e.g.: breast cancer screening)

**Tertiary Prevention:** Goal is to improve quality of life and/or reduce the symptoms of diseases you already have. (e.g.: Cardiac Rehabilitation Program)





## Caveats

---

- Recommendations consider guidelines for older adults (eg: US Preventive Task Force, American Cancer Society)
- Individuals with Dementia are often excluded from research that supports these guidelines.
- Recommendations ultimately rely on expert opinion and personal clinical experience



## Primary Prevention

---

Goal is to prevent getting a disease



# Vaccinations-CDC Recommendations

---

Td: Once every 10 years.

Pneumonia 23-valent: All adults >65 years.

Pneumonia 13-valent: Recommended for adults with a condition that weakens the immune system, CSF leak or cochlear implant. \*\*nursing home residents are at higher risk than general population.

Influenza: Yearly

Shingles: Healthy adults >50 years.

COVID: Recommended (residents of nursing homes priority 1a).



## Exercise

---

- Unclear if exercise lowers the risk of getting Dementia or slows its progression
- Exercise can help with mood and other comorbidities (HTN, heart disease)
- Moderate to Severe Dementia often leads to increased apathy to activities the person with dementia used to enjoy
- Exercise can help maintain functionality (possibly minimizing future caregiver burden).
- Persons with Dementia are more likely to gain from PT referrals if a caregiver can attend with them.

# Diet

---

- No known dietary cure to decrease risk of Dementia or limit progression of Dementia.
- A healthy diet is important to decrease the risk of other chronic diseases that may impact the risk of Dementia (esp. Vascular sub-type).
- Dementia may impact appetite, swallow and cravings
- Feeding tubes are not recommended to either minimize aspiration or extended life.

## Secondary Prevention

---

Goal is to detect a disease early to prevent it from getting worse



## Breast Cancer

---

- USPSTF (2016) recommends screening via mammogram of all women ages 50-74 biennially. **No evidence exists for women >75.**
- ACS (2015) recommends annual screening from 45 to 54 with opportunity to transition to biennial screening at 55. **Continue if health is good and life expectancy of 10 years or longer.**
- Breast self-exam and clinical screening exams are no longer recommended.



## Prostate Cancer

---

- USPSTF (2018): Ages 55-69 shared decision making. **>70, do not screen.**
- ACS (2010): Men 50 and older with **at least 10-year life expectancy** should discuss pros and cons of screening with doctor and make informed decision.

# Colon Cancer

---

- USPSTF (2020-Draft) recommends screening from ages 50 to 75 for colon cancer with **shared decision making for ages 76-85 and recommendation against screening if >85.**
  - Screening most often includes either lab test (FOBT or FIT) yearly or colonoscopy at least every 10 years (more frequently depending on risk factors)
  - **Re: 76-85 cohort:** "Evidence indicates that the net benefit of screening all persons in this age group is small. In determining whether this service is appropriate in individual cases, patients and clinicians should consider the patient's overall health and prior screening history."
- ACS (2018) recommends people who are in **good health** and with a **life expectancy of more than 10 years** should continue regular colorectal cancer screening through age 75. Ages 76-84 decision based on preferences, life expectancy, overall health and prior screening history. Over 85 should no longer get colorectal cancer screening.

[HTTPS://WWW.DEMENTIA.ORG.AU/FILES/HELPSHEETS/HELPSHEET-DEMENTIAQANDA20-ANAETHESIA\\_ENGLISH.PDF](https://www.dementia.org.au/files/helpsheets/helpsheet-dementiaqanda20-anaesthesia_english.pdf)

# Lung Cancer

---

- USPSTF (2020-Draft) recommends annual screening for patients ages 50-80 with at least a 20-pack year history of smoking who are currently smoking or who have quit within the last 15 years
  - Data based on study that enrolled adults up to age 74 (only 10% of sample >70 y/o).
  - Original study **excluded** those who were unlikely to complete a curative lung cancer surgery or those with conditions that gave them a **substantial risk of death in the next 8 years.**
  - **"Screening may not be appropriate for patients with substantial comorbid conditions,** particularly those at the upper end of the screening range"
- ACS recommends screening in ages 55-74 and good health (30 pack year history).

## Cervical Cancer

---

- USPTF (2018): Screening can stop once a woman reaches 65 IF she has a history of 3 negative tests in a row OR a history of hysterectomy including the cervix AND no history of abnormal PAP (CIN II or greater). Once screening has stopped it should not start again even if patient reports a new sexual partner.



## Cancer Screening in Dementia-Summary

---

- Given an average prognosis of 4-8 years for patients with all kind of Dementia and horizon to benefit estimated at 10 years, **cancer screening should be discouraged.**
- Patients with Dementia are at **heightened risk of delirium associated with anesthetic** and should be particularly be encouraged to consider this risk when weighing the risks and benefits of colon cancer screening with direct visualization.



## Osteoporosis

---

- USPSTF (2018): recommends screening for osteoporosis in women 65 years and older. Insufficient evidence for men.
- Endocrine Society (2012): We recommend testing higher risk men (aged  $\geq 70$  or aged 50-69 who have risk factors (e.g. low body weight, prior fracture as an adult, smoking, etc.).
- Horizon to Benefit of osteoporosis treatment to limit risk of future fracture estimated in the 2-5-year range.**
- If treating, consider IV bisphosphonates**
  - Memory concerns with once weekly therapy and need to remain upright after oral administration.



BERRY SD, SHI S, KIEL DP. CONSIDERING THE RISKS AND BENEFITS OF OSTEOPOROSIS TREATMENT IN OLDER ADULTS. *JAMA INTERN MED.* 2019;179(8):1103-1104. DOI:10.1001/JAMAINTERNMED.2019.0688

## Abdominal Aortic Aneurysm

---

- USPTF (2019): 1-time screening recommended in men ages 65-75 who have ever smoked. Screening is NOT recommended in women who have never smoked (insufficient evidence for women with a history of smoking).
- Limited evidence of risk/benefit with less invasive endoscopic approaches, however, do not currently recommend screening for those with Dementia.



## Hearing Loss Screen

---

- USPTF (2012) Insufficient evidence to screen for hearing loss in adults ages 50 years and older.
- Hearing loss is a risk factor for a Dementia
  - Impact attention/memory
  - Impact test performance
- Pocket talker vs. Hearing Aids



## Vision Screen

---

- USPTF (2016): Insufficient evidence to assess the balance of benefits and harms of screening for impaired visual acuity or open angle glaucoma (2013) in older adults.
- CDC STEADI campaign recommends vision screen for older adults at high risk of falls



# Hypertension

---

- American Heart Association/JNC 8 (2014): **goal BP in patients >60 should be <150/90.**
  - If history of Diabetes goal <140/90 regardless of age
- **SPRINT-Senior Trial (2016):**
  - Sub-analysis of patients >75 y/o in SPRINT trial. Showed better cardiovascular outcomes in patients with **goal of SBP <120** as compared with <140. (similar rates of falls and orthostatic hypotension in both arms). \*\*of note **patients with Dementia were excluded from this study**
- **Avoid overtreatment in patients with Dementia**
  - Home vs. In-Office BP values (white coat hypertension!)
  - Falls, Hyponatremia, AKI risks (re-consider diuretics in particular)
  - Watch for changing dose needs with weight loss!

# Diabetes Management

---

- American Geriatrics Society: **Goal A1c 7.5-8%** in older patients with moderate comorbidities and a life expectancy of less than 10 years.
- American Diabetes Association recommends 8-8.5% A1c goal for older patients with complex medical issues.
- ACCORD/ADVANCE trial secondary analysis showed increased risk of cardiovascular events in patients with high risk of hypoglycemia (likely 2/2 catecholamine surges).
- Dementia is a major risk factor for hypoglycemia.

Lipska KJ, Krumholz H, Soones T, Lee SJ. Polypharmacy in the Aging Patient: A Review of Glycemic Control in Older Adults With Type 2 Diabetes. JAMA. 2016 Mar 8;315(10):1034-45.

# Hyperlipidemia

---

- Limited evidence available from current clinical trials for patients >75 or patients with Dementia
- Yourman et al with 2020 article demonstrating in patients 50 to 75 y/o without a history of coronary artery disease it takes 2.5 years of statin administration to prevent one major cardiac event (eg: heart attack, stroke).
- Awaiting results of **STAREE** trial which will examine time to benefit for statins in patients 70 and older.

Yourman LC, Cenzer IS, Boscardin WJ, Nguyen BT, Smith AK, Schonberg MA, Schoenborn NL, Widera EW, Orkaby A, Rodríguez A, Lee SJ. Evaluation of Time to Benefit of Statins for the Primary Prevention of Cardiovascular Events in Adults Aged 50 to 75 Years: A Meta-analysis. JAMA Intern Med. 2020 Nov 16

# How to Talk about Limiting Secondary Prevention Efforts

---

- “offering a discussion of life expectancy to patients while prefacing that patients can decline was acceptable to most older adults”
- “helpful to discuss what alternative health issues would be prioritized, such as addressing active symptoms patients may have, instead of cancer screening so as to not feel like they were receiving less care”
- “this test would not help you live longer” was more preferred over “you may not live long enough to benefit from this test.”



NANCY L. SCHOENBORN, MD, MHS, CYNTHIA M. BOYD, MD, MPH, SEI J. LEE, MD, MAS, DANIELLE CAYEA, MD, MS, CRAIG E. POLLACK, MD, MHS, COMMUNICATING ABOUT STOPPING CANCER SCREENING: COMPARING CLINICIANS' AND OLDER ADULTS' PERSPECTIVES, THE GERONTOLOGIST, VOLUME 59, ISSUE SUPPLEMENT 1, JUNE 2019, PAGES S67-S76, [HTTPS://DOI.ORG/10.1093/GERONT/GNY172](https://doi.org/10.1093/GERONT/GNY172)

# Language Preferences in Limiting Secondary Prevention for Colon Cancer

Explanation	Phrase
Other health priorities	Your other health issues should take priority.
Guidelines	Colonoscopy is not recommended for you by medical guidelines.
Unlikely to benefit	You are unlikely to benefit from the colonoscopy.
Age	We usually stop doing colonoscopies at your age.
At risk for harms	You are at high risk for harms from the colonoscopy.
Quality of life	We should focus on quality of life instead of looking for cancer.
Downstream tests	The colonoscopy can lead to unnecessary tests or treatments.
Would not help live longer	The colonoscopy would not help you live longer.
Discomfort	The colonoscopy can be very uncomfortable.
Inconvenience	The colonoscopy can be very inconvenient to complete.
No discussion	The doctor does not mention colonoscopy.*
May not live long enough	You may not live long enough to benefit from the colonoscopy.
No explanation	The doctor does not give an explanation.*

Schoenborn NL, Crossnohere NL, Janssen EM, Pollack CE, Boyd CM, Wolff AC, Xue OL, Massare J, Blinka M, Bridges JFP. Examining Generalizability of Older Adults' Preferences for Discussing Cessation of Screening Colonoscopies in Older Adults with Low Health Literacy. J Gen Intern Med. 2019 Nov;34(11):2512-2519.

## Tertiary Prevention

Goal is to improve quality of life and/or reduce the symptoms of diseases you already have.



## Anticipatory Guidance: Goals of Care

- Discussing a patient's goals for their care is essential in early Dementia to ensure the patient's preferences are heard.
- A Dementia specific Advanced Directive is available:  
<https://dementia-directive.org/>
- COVID-19 presents an excellent opportunity to document goals of care.



INSTRUCTIONS

FAQS

RESOURCES

IN THE NEWS

## Anticipatory Guidance: Durable Power of Attorney for Healthcare and Finances

- Early Dementia is also an important time to designate and complete legal paperwork for power of attorney for health care and finances.
- The power of attorney will only speak for the patient when the patient does not have capacity to speak for themselves.
  - Patient capacity is not fixed and can vary depending on the time of day or complexity of the question.
- Consider seeking the advice of an elder law attorney: <https://www.naela.org/findlawyer>

## Anticipatory Guidance: Driving

---

- At time of Dementia diagnosis starting planning for when to limit and stop driving (including making plans for alternative transportation)
  - Risks include accidents, getting lost, driving too slowly, harm of others/legal liability
- OT and/or Neuro-Psychiatry testing can help weigh in on patient driving safety. Department of Licensing also does safe driving exams.

[HTTPS://S0.HFDSTATIC.COM/SITES/THE\\_HARTFORD/FILES/CMME-CROSSROADS.PDF](https://s0.hfdstatic.com/sites/THE_HARTFORD/FILES/CMME-CROSSROADS.PDF)

## Anticipatory Guidance: Driving Resource Hartford Center

---

“The guide provides suggestions for monitoring, limiting and stopping driving. The information incorporates the experiences of family caregivers and people with dementia, as well as suggestions from experts in medicine, gerontology and transportation.”

### SAFE DRIVING FOR A LIFETIME



### AT THE CROSSROADS

Family Conversations About Alzheimer's Disease,  
Dementia & Driving

THE HARTFORD  
Center for  
Mature Market  
EXCELLENCE®

## Anticipatory Guidance: Driving Resource Alzheimer's Association

- "For people in the early stages of Alzheimer's, it is never too soon to plan ahead for how you will get around when you can no longer drive. Putting a plan in place can be an empowering way to make your voice heard."

Watch how four families deal with different issues related to dementia and driving.



<https://www.alz.org/help-support/caregiving/safety/dementia-driving>

## Anticipatory Guidance: Gun Safety

For patients in the early stages of dementia, Sussman says she might tell them, "You're going to need to retire from driving and retire from the use of firearms.' Which changes it from, 'We need to take these away' or 'You need to stop.' So let's plan."

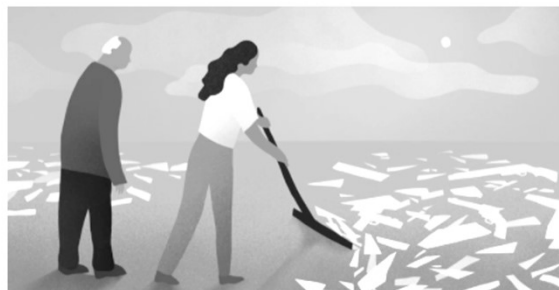
### Firearms And Dementia: How Do You Convince A Loved One To Give Up Their Guns?

November 13, 2018 7:15 AM ET  
Heard on Morning Edition

 MELISSA BLOCK

 5-Minute Listen

+ PLAYLIST



## Anticipatory Guidance: Home Safety Evaluation

- Excellent checklist for home-safety assessment at: <https://www.alz.org/help-support/caregiving/safety/home-safety>
- Also consider formal Home Health Occupational Therapy referral.
  - Assist with door disguise or alternative lock systems to minimize wandering
  - Address tripping hazards to limit falls
  - Assess the need for assistive devices to make bathing and ambulating safer.
- Cooking/Hot Water and Risks of Burns



Before

Stairwell Door #1

After

## Anticipatory Guidance: Avoiding Hospitalization

- Dementia is associated with 2x the risk of Hospitalization as similarly aged adults.
- Hospitalization of patients with Dementia can be Harmful:
  - Increased risk of Delirium
  - Functional loss from limited mobilization
  - Iatrogenic errors/harm
    - Treating Dementia Associated Behaviors
    - Not recognizing changes from patient's baseline
    - Attributing symptoms inappropriately to Dementia

PHELAN EA, BORSON S, GROTHAUS L, BALCH S, LARSON EB. ASSOCIATION OF INCIDENT DEMENTIA WITH HOSPITALIZATIONS. JAMA. 2012;307(2):165-172. DOI:10.1001/JAMA.2011.1964

## Anticipatory Guidance: Caregiver Burnout

- Caregivers of patient's with Dementia are at higher risk of burnout than caregivers to patients with other medical conditions.
  - 2/3 are women and approximately 1/3 are >65.
  - 30-40% report having depression
  - Many resources exist to help!
- A small sampling of resources:
  - Alzheimer's Association
  - Area Agency on Aging (Adult Day Health Program, Respite Links, Caregiver Support Groups)
  - Memory Brain Wellness Clinic-UW



### Be a Healthy Caregiver

mon, April 20, 10:00am

Every Monday in April, 10 – 11 a.m., come together with 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.



## Anticipatory Guidance: COVID-19 challenges

- COVID-19 infection and Delirium.
- Hospital visitor policy exceptions for Dementia patients requiring caregivers.
- Unique caregiving challenges.
- CDC guidance: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/caregivers-dementia.html>
- Alzheimer's Association guidance: <https://www.alz.org/professionals/professional-providers/coronavirus-covid-19-tips-for-dementia-caregivers>
- Great video on talking to loved one with Dementia about COVID-19: <https://www.workingdaughter.com/talking-to-a-parent-with-dementia-who-is-in-lock-down-due-to-covid-19/>



## In Review:

---

- Dementia is a terminal illness and on average the prognosis from diagnosis to death is 4-8 years.
- If the horizon to benefit of a preventive therapy is longer than 4-8 years, it is unlikely to benefit patients with Dementia (including cancer screening).
- Some preventive care has an appropriate Horizon to Benefit (e.g. screening/treatment for osteoporosis and providing anticipatory guidance about plans to enhance safety and quality of life living with Dementia).
- Patient centered care will ensure that the goals of the person with Dementia and their family remain front and center for all medical decision making.

## Questions?

---

