1

Managing Chronic Diseases in People Living with Dementia

Collin Burks, MD
January 15th, 2025
Assistant Professor, Division of Geriatrics, Duke School of Medicine

2

Objectives

- Highlight the complexities managing chronic health conditions when dementia is also present
- Describe practical considerations for changes in management of chronic conditions

3

Outline

- Brief introductions to chronic diseases and dementia
- Dementia and chronic disease management
- Examples:
  - High blood pressure
  - Diabetes
  - COPD
  - Heart failure
- Conclusion and questions

4

What are Chronic Diseases?

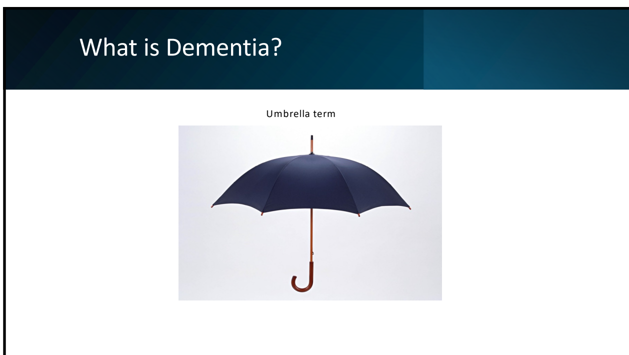
- Common chronic diseases in the US include:
  - Obesity
  - High blood pressure
  - High cholesterol
  - Coronary heart disease
  - Chronic obstructive pulmonary disease (COPD)
  - Asthma
  - Chronic kidney disease
  - Diabetes
  - Cancer
  - Dementia
  - Among many others!

About Chronic Diseases. U.S. Centers for Disease Control and Prevention. October 2024. Accessed January 2025. https://www.cdc.gov/chronic-disease/about/index.html

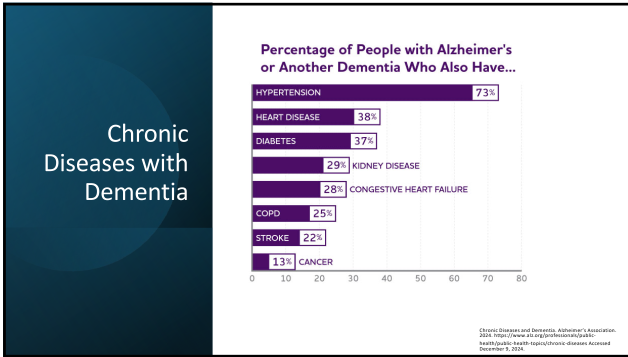
5

What is Dementia?

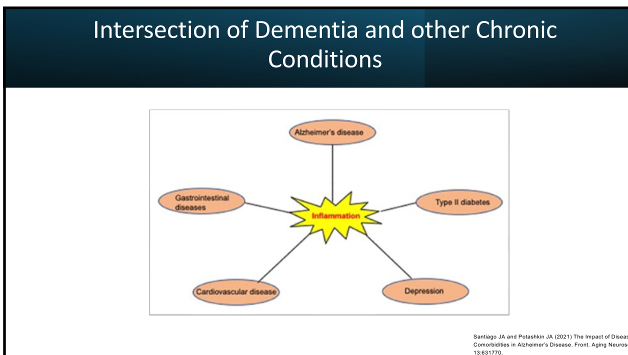
Umbrella term



6



7



8

What is Chronic Disease Management?

- Comprehensive approach to the care and treatment of chronic conditions
- Patient self-management is a key principle

9

Patient Self-Management

- Five key areas:
  - Identifying problems and generating solutions
  - Making decisions
  - Utilizing resources
  - Working with healthcare providers
  - Taking action

Lorig K, Holman H. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med*. 2003;26(1):1–7.

10

How does the addition of dementia change chronic disease self-management?

- A person's ability to self-manage their chronic disease changes as various cognitive domains are impacted in dementia
  - Memory deficits: difficulty remembering to take medications
  - Executive function deficits: difficulty deciding on how to manage a high blood sugar reading
  - Visuospatial deficits: difficulty using inhaler

Ibrahim JE, Anderson LJ, MacPhail A, Lovell JJ, Davis MC, Winbolt M. Chronic disease self-management support for persons with dementia, in a clinical setting. *J Multidiscip Healthc*. 2017;10:49-58. Published 2017 Jan 25. doi:10.2147/JMDH.S121626

11

How does the addition of dementia change chronic disease management in general?

- Patient self-management changes
- Higher risk of adverse effects
- Communication becomes even more important
- Goals and priorities change over time
- Patients need strategies tailored specifically to them

12

Sample Patient Example

Mr. G is a 74-year-old man with a history of type 2 diabetes, high blood pressure, congestive heart failure, and chronic obstructive pulmonary disease (COPD). He lives with his wife and dog in Durham. He has managed his medications, including insulin injections, for several decades. However, over the last year, he stopped checking his blood sugar as frequently, no longer weighs himself regularly, and uses his daily inhalers at random. He has been hospitalized twice for heart failure exacerbations. He has not paid the last three utility bills, which he had done faithfully for 50 years.

13

Mr. G and Diabetes

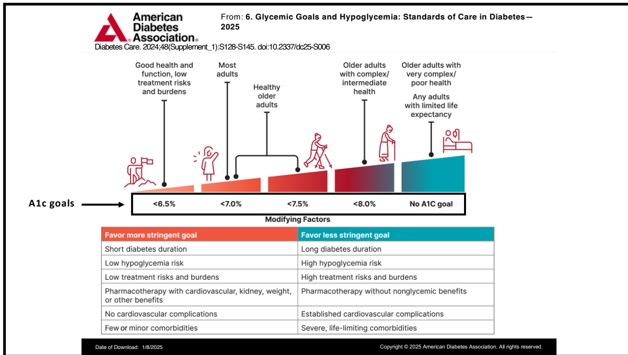
Mr. G and his wife come to my clinic to establish care for dementia. We review his emergency room visit for a urinary tract infection. When he got to the emergency room, his blood sugar was low. No changes were made to his diabetes medications, and he was sent home on antibiotics. For his diabetes, he takes insulin at night as well as with his meals. His wife wonders whether he sometimes forgets that he has taken his mealtime insulin and gives himself an extra dose. Mr. G really wants to keep his A1c, a marker of his average blood sugar, under 6.5, as he has always been told to do so. He wants to stay healthy so he can keep walking his dog.

14

Diabetes and Dementia

- High prevalence of cognitive impairment in people with diabetes
- Low blood sugar itself can increase risk of cognitive impairment
- Lack of awareness of low blood sugars can be significant

15



Favor more stringent goal	Favor less stringent goal
Short diabetes duration	Long diabetes duration
Low hypoglycemia risk	High hypoglycemia risk
Low treatment risks and burdens	High treatment risks and burdens
Pharmacotherapy with cardiovascular, kidney, weight, or other benefits	Pharmacotherapy without nonglycemic benefits
No cardiovascular complications	Established cardiovascular complications
Few or minor comorbidities	Severe, life-limiting comorbidities

16

Diabetes Management in Dementia

- American Diabetes Association recommendations for A1c in people with cognitive impairment:
  - For someone with mild-to-moderate cognitive impairment, reasonable A1c goal < 8, fasting glucose 90-150
  - For someone with moderate-to-severe cognitive impairment, ignore the A1c, fasting glucose 100-180

17

Recommendations for Mr. G

- Discuss his A1c goal – perhaps < 8.0 instead
- Consider obtaining a continuous glucose monitor
- Talk to his provider about simplification of regimen

18

Recommendations for Mr. G

- Attend cognitive rehabilitation with an occupational or speech therapist
- Checklist on fridge to mark off insulin doses
- Organizing pills – weekly pill container or blister pack?
- Connect with the Duke Dementia Family Support Program

19

Mr. G and High Blood Pressure

Two years later, Mr. G comes to my clinic with his wife for a routine follow-up of dementia. We note that his blood pressure is elevated in the clinic at 155/95. He has been on 2 blood pressure medications for several years. Mrs. G wonders whether he should measure his blood pressure daily.

20

High blood pressure and dementia

- High blood pressure is very common in people with dementia
- Associated with Alzheimer's dementia as well as vascular dementia

21

Recommendations for Mr. G

- Home monitoring prior to next primary care visit: measure blood pressure twice daily for 5-7 days, write down the readings
  - Most people do not need to measure their blood pressure daily, unless directed to by their provider
- Talk to his primary care provider (or cardiologist, if he has one) about his blood pressure goal
- Refer him to a chronic care management program

22

Follow these steps for an accurate blood pressure measurement

1. PREPARE

Avoid caffeine, smoking and exercise for 30 minutes before measuring your blood pressure.

Wait at least 30 minutes after a meal.

If you're on blood pressure medication, measure your BP *before* you take your medication.

Empty your bladder beforehand.

Find a quiet space where you can sit comfortably without distraction.

2. POSITION

3. MEASURE

Rest for five minutes while in position before starting.

Take two or three measurements, one minute apart, twice daily for seven days.

Keep your body relaxed and in position during measurements.

Sit quietly with no distractions during measurements—avoid conversations, TV, phones and other devices.

Record your measurements when finished.

Scan on your phone's camera app to open this webpage

©2023 American Medical Association. All Rights Reserved.
07/23 IHO23-0006

This Prepare, position, measure handout was adapted with permission of the American Medical Association and The Johns Hopkins University. The original copyrighted content can be found at https://www.ama-assn.org/ama-johns-hopkins-blood-pressure-resources.

23

COPD and dementia

Two years later, Mr. G comes to clinic for a routine follow-up for dementia. He has been hospitalized twice for COPD exacerbations. The last hospital team referred him for pulmonary function tests since it had been 10 years since his last tests, and for pulmonary rehab. He seems to be having trouble using his inhalers and in following other multi-step directions. Mrs. G is now completing managing his other medications. He has had 3 falls in the last year. He has retired from driving.

24

COPD and dementia

- Increased prevalence of cognitive impairment in people with COPD
- Assessing severity of disease can be difficult

25

Recommendations for Mr. G

- Talk to his provider about whether further tests will change treatment, or a simpler test
- When available, switch inhalers to nebulizers
- Instead of outpatient pulmonary rehab, consider home physical therapy

26

- Consider talking with your provider about whether an action plan may be helpful

American Lung Association.

My COPD Action Plan

Patients and healthcare providers should complete this action plan together.
This plan should be discussed at each visit and updated as needed.

The green, yellow and red zones show symptoms of COPD. The list of symptoms is not complete. You may experience other symptoms. In the "Actions" column, your healthcare provider will recommend actions for you to take. Your healthcare provider may write down other actions in addition to those listed here.

Green Zone: I am doing well today	Actions
• Usual activity and exercise level • Usual amounts of cough and phlegm/mucus • Sleep well at night • Appetite is good	☐ Take daily medicines ☐ Use oxygen as prescribed ☐ Continue regular exercise/diet plan ☐ Avoid tobacco product use and other inhaled irritants ☐ ______

Yellow Zone: I am having a bad day or a COPD flare	Actions
• More breathless than usual • I have less energy for my daily activities • Increased or thicker phlegm/mucus • Using quick relief inhaler/nebulizer more often • More swelling in ankles • More coughing than usual • I feel like I have a "chest cold" • Poor sleep and my symptoms woke me up • My appetite is not good • My medicine is not helping	☐ Continue daily medication ☐ Use quick relief inhaler every ____ hours ☐ Start an oral corticosteroid (specify name, dose, and duration) ______ ☐ Start an antibiotic (specify name, dose, and duration) ______ ☐ Use oxygen as prescribed ☐ Get plenty of rest ☐ Use pursed lip breathing ☐ Avoid secondhand smoke, e-cigarette aerosol, and other inhaled irritants ☐ Call provider immediately if symptoms do not improve ☐ ______

Red Zone: I need urgent medical care	Actions
• Severe shortness of breath even at rest • Not able to do any activity because of breathing • Not able to sleep because of breathing • Fever or shaking chills • Feeling confused or very drowsy • Chest pains • Coughing up blood	☐ Call 911 or seek medical care immediately ☐ While getting help, immediately do the following: ☐ ______

The information contained in this document is for educational use only. It should not be used as a substitute for professional medical advice, diagnosis or treatment. THE AMERICAN LUNG ASSOCIATION DOES NOT ENDORSE ANY PRODUCT, DEVICE OR SERVICE, INCLUDING ANY PARTICULAR COPD MEDICATION OR TREATMENT DEVICE. For more information, visit www.Lung.org or call 1-800-LUNG-USA (1-800-586-4872) © 2015 American Lung Association

1-800-LUNG-USA | Lung.org/copd

ALA COPD AP V3 6 15 2022

Scan on your phone's camera app to open this webpage

My COPD Action Plan. American Lung Association. 2022. Accessed January 2025.

https://www.lung.org/getmedia/c7657648-a30f-4465-af92-fc762411922e/fy21-ala-copd-action-plan.pdf

27

Mr. G and congestive heart failure

Three years later, Mr. G comes to clinic. He had a heart attack last year and his heart failure has progressed significantly. He spent three weeks at a skilled nursing facility for rehab and did not have a good experience. He has gone to his cardiologist numerous times over the last year, and he is on several new medications. It seems that one of these medications is quite expensive. He spends most of his time in his chair and seems tired all the time. His appetite is poor. Mrs. G has a difficult time trying to weigh him every morning.

28

Congestive heart failure and dementia

- Common for people with heart failure to have cognitive impairment
- Heart failure + cognitive impairment = 2x risk of being re-admitted to a hospital

29

Recommendations for Mr. G

- Comprehensive review of medications
- Talk to cardiologist about other ways to monitor for fluid gain besides weighing
- Consider involving palliative care now (or earlier)
- Review the financial burden of his medications

30

Summary of General Recommendations

- Explicit discussions on goals and priorities
- Pill containers
- Cognitive rehabilitation
- Chronic care management programs
- Action plans
- Involvement of palliative care
- Discussions around financial burden
- Connecting with Duke Dementia Family Support Program

31

How can I figure out my priorities?

- What matters most to you in your life?

32

Identifying My Health Priorities

Welcome To My Health Priorities!

https://myhealthpriorities.org

Through this process, we will help you identify what matters most to you—**Your Health Priorities.**

Why Are Your Health Priorities Important?

What matters most in life and health is different for everyone, particularly if you have multiple chronic conditions. The more you and your health care team know about what matters most to you, the better you can work together to **make the right decisions for you.**

Use the "Back" button to move to the previous page.

Use the "Next" button to move to the next page.

Back · Welcome · What Matters · Health Goals · Bothersome Problems · Top Priority · Health Care · Share Priorities · Next

Disclaimer: The information and material contained on or produced by this website, is for general, informational purposes only and is not intended for diagnostic use or medical decision-making. Please read our disclaimer for more information.

About • Site Policies • Legal Disclaimer

© Copyright 2024 Mary Tinetti and Aanand Naik. All rights reserved. myhp-intro-0

Scan on your phone's camera app to open this webpage

Tinetti M and Naik A. Identifying My Health Priorities. 2024. Accessed January 2025. https://myhealthpriorities.org

33

1. Identify What Matters Most to You
2. Identify Your Health Goal
3. Identify Your Bothersome Symptoms or Health Problems
4. Clarify The Top Priority You Most Want To Focus On
5. Identify Your Burdensome Medications and Health Related Tasks

Next, We Want To Identify What Is Most Bothersome To You That Is Keeping You From Your Goal

Select up to three of your most bothersome symptoms or health problems from the list below (***Scroll for more options***)

If your most bothersome symptom or health problem isn't listed, select 'other' and type it into the box at the top.

- Other
- Feeling muscle weakness
- Feeling pain
- Feeling unsteady; trouble balancing/walking
- Feeling worried, nervous, anxious
- Feeling sad
- Feeling irritable
- Feeling adverse effects from treatment(s)
- Feeling dizzy
- Feeling tired/lacking energy
- Having trouble sleeping
- Having poor eyesight
- Having poor hearing
- Having leg swelling
- Having trouble breathing (short of breath)
- Having health care tasks take too much time
- Having urinary incontinence
- Having to go to the bathroom often
- Having diarrhea
- Having constipation
- Having upset stomach, nausea
- Having confusing or memory problems

Tinetti M and Naik A. Identifying My Health Priorities. 2024. Accessed January 2025. https://myhealthpriorities.org

34

myhealth priorities

Your Health Priorities Summary

My Top Priority
The one problem I want to focus on is: Having health care tasks take too much time
So I can: I want to spend time with my grandchildren two times a week

What Matters Most:
- Avoiding spending time in the hospital
- Taking care of myself
- Doing activities with family and friends
- Reducing the amount of time I devote to health care

Most Important Health Goal:
I want to spend time with my grandchildren two times a week

Most Bothersome Symptoms or Health Problems:
- Feeling adverse effects from treatment(s)
- Having health care tasks take too much time
- Feeling tired/lacking energy

Current Burdensome Health Care Tasks and Medications
- Checking health signs (e.g., weight, blood pressure)
- Wearing CPAP mask
- Having Surgeries
- Going through other Diagnostic Tests (e.g. mammography)
- Visiting specialists (e.g., cardiologist, pulmonologist, urologist)
- Transportation
- carvedilol
- jardiance

Current Helpful Tasks That I Wouldn't Want Changed
- Using a cane or walker
- Having Blood Tests done
- Having X-Rays done
- Visiting PCP primary clinician
- Visiting counselor (e.g., psychologist, social worker, therapist)
- In-home help
- Following a special diet

Patients/care partners: Tips to share your priorities with your health care team

- **At each visit, ask your health care team to review your top priority.**
- **Ask for help with your most important health goal.**
  Example: 'Is there something to help me walk around at home with less shortness of breath?'
- **Ask if treatments will help your most important health goal.**
  Example: 'Will the treatment improve breathing enough to get lunch with friends every day?'
- **Ask what the expected treatment effort would be.**
  Example: 'What exactly will I have to do on my own if we start insulin?'

Health professionals: Tools to align care and decision-making with patients' health priorities, https://PatientPrioritiesCare.org/health-professional-toolkit/

35

Concluding the talk

- Chronic disease management is even more complex when dementia is present, however there are helpful tools and resources
- Keeping patients' goals and priorities at the forefront are key

36

References

- About Chronic Diseases. U.S. Centers for Disease Control and Prevention. October 2024. Accessed January 2025. https://www.cdc.gov/chronic-disease/about/index.html
- How to Measure your Blood Pressure at Home. American Medical Association. 2023. Accessed January 2025. https://www.ama-assn.org/system/files/2020-11/smbp-infographic.pdf
- Catic, Angela. Dementia and Chronic Disease: Management of Comorbid Medical Conditions. Springer International Publishing; 2020.
- Chronic Diseases and Dementia. Alzheimer's Association. 2024. https://www.alz.org/professionals/public-health/public-health-topics/chronic-diseases Accessed December 9, 2024.
- Diabetes Care. 2024;48(Supplement_1):S128-S145. doi:10.2337/dc25-S006
- Diabetes Care. 2024;48(Supplement_1):S266-S282. doi:10.2337/dc25-S013
- Ibrahim JE, Anderson LJ, MacPhail A, Lovell JJ, Davis MC, Winbolt M. Chronic disease self-management support for persons with dementia, in a clinical setting. *J Multidiscip Healthc*. 2017;10:49-58. Published 2017 Jan 25. doi:10.2147/JMDH.S121626
- Lorig K, Holman H. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med*. 2003;26(1):1–7.
- My COPD Action Plan. American Lung Association. 2022. Accessed January 2025. https://www.lung.org/getmedia/c7657648-a30f-4465-af92-fc762411922e/fy21-ala-copd-action-plan.pdf
- Santiago JA and Potashkin JA (2021). The Impact of Disease Comorbidities in Alzheimer's Disease. Front. Aging Neurosci. 13:631770.
- Tinetti M and Naik A. Identifying My Health Priorities. 2024. Accessed January 2025. https://myhealthpriorities.org

37

38