



Toolkit for Caregivers

How health literacy can help you and the people you care for with dementia.



A division of Wisconsin Literacy, Inc. | Supported by a grant from RRF Foundation for Aging

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Toolkit Goals

- Improve the health, health care, and caregiving for people who have dementia.
- Help family members and caregivers communicate better with health providers, people with dementia, and family members.

Use this toolkit to:

- Improve your health literacy. (We talk about health literacy on page 3)
- Communicate better with doctors, family members, and people you care for.
- Plan and coordinate care.
- Find resources that can help you and people you care for.



“Alzheimer’s show’s no gratitude, sympathy or empathy... so as the caregiver you must show all 3.”

–attributed to Deb Harrison of the co-creation team

What is Dementia?

Dementia is a brain disease.

Brain disease affects a person's memory, thinking, and social abilities.

Dementia is not a normal part of aging.

A person with dementia might not be able to do everyday activities.



Alzheimer's disease is the most common type of dementia.

We don't have a cure for Alzheimer's disease, but we can improve the quality of life for people who have Alzheimer's and for their caregivers.

Improving health literacy is the first step.

Part 1 Health Literacy

What is health literacy?

Almost everyone will have difficulty understanding and using health information at some time.

There are 2 sides to health literacy:

1. A patient's ability to access, understand and use their health information.
2. A provider's or caregiver's ability to communicate health information in a way patients can understand.

People with low health literacy may have difficulty:

- finding health services.
- understanding spoken and written communication from doctors and caregivers.
- sharing information with doctors, caregivers, and family members.
- filling out forms.
- managing other chronic health conditions.
- taking medicine correctly.
- reading medicine labels.
- using health insurance.

What is the strongest predictor of someone's health status?

- a. Age
- b. Income
- c. Literacy skills
- d. Employment status
- e. Education level
- f. Race or ethnic group

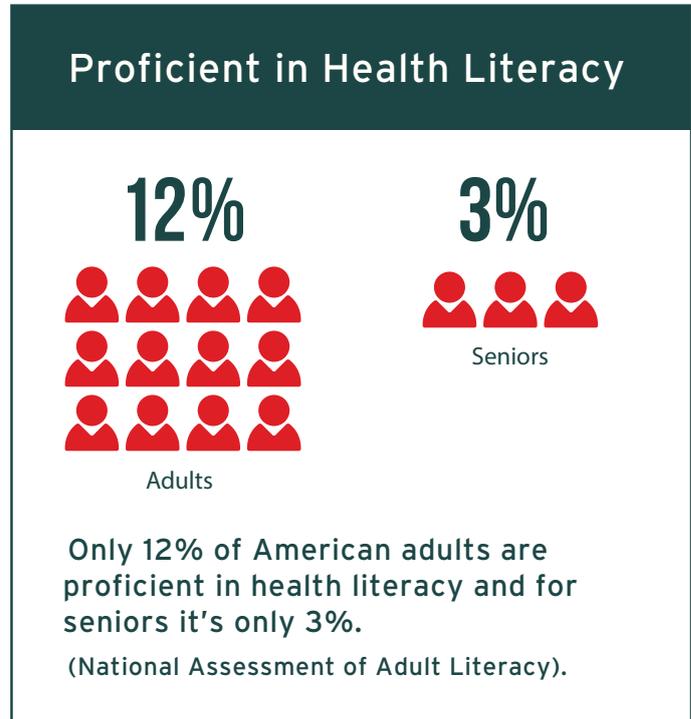
Answer: C

Who is at risk for low health literacy?

- Only 3 out of 100 seniors can evaluate information to decide which legal document applies to a specific health care situation.
- Almost 60 out of 100 seniors have basic or below basic health literacy. They can circle the appointment date on a hospital appointment slip, but not much more.

Older adults are at risk for lower health literacy for many reasons:

- physical changes
- psychological changes
- cognitive changes



Why older adults?

Older adults have:

- decreased reading skills.
- decreased hearing and vision.
- more depression and anxiety.
- difficulty processing and understanding information.
- short term memory loss.
- more chronic illnesses, so they use more medical services.
- more risk for medication mistakes because they take more medication.

20% of American adults read at or below the 5th grade reading level

45% read at the lowest reading level

How does improved health literacy help caregivers?

Using health literacy strategies and resources can help you:

- take better care of the people you love.
- feel more confident and satisfied in the care you provide.
- communicate better with health professionals and other family members.
- support people with dementia, so they can stay in their current living situation longer.

Increased medicine safety

Following medicine instructions can be difficult, and medicine mistakes can be very serious, even deadly.

Help the people you care for stay safe:

Schedule a consultation with a pharmacist or health provider to review all medicines.

- Some consultations are free.

Ask the pharmacist or doctor all your questions. You can ask:

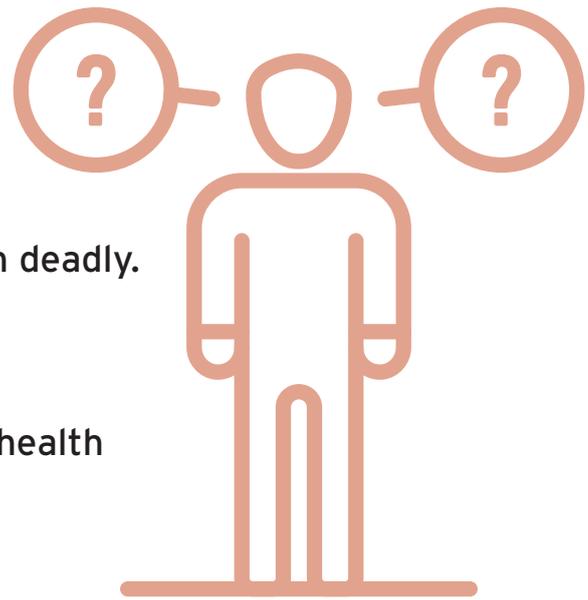
- when you pick up a prescription.
- during a pharmacy consultation.
- at the doctor's office.
- by calling your pharmacy or doctor's office.

Use a pill box to remember when to take medicine.

- Electronic pill boxes have timers that make a sound when a person needs to take medicine.

Write a list of all current medicines.

- Add pictures of the medicine to show the shape, size, and color of each pill.



Ask about other forms of medicine if the person you care for cannot swallow a pill. For example:

- dissolving pills - dissolve in mouth
- liquid medicine
- powder medicine

Be Careful!

Sometimes pharmacies use different pill manufacturers, so pill colors, sizes, and shapes can be different from one refill to the next. This can be confusing and cause medicine mistakes. Take a list of all medicines to the pharmacy and ask if there are any manufacturer changes.

For every new medicine (prescription, over-the-counter, or vitamin), always ask the pharmacist about side effects and bad reactions with other medicine.

It's best to ask a pharmacist, but you can also use this resource from AARP: [Drug Directory, Side Effects, and Interaction Checker](#)

Part 2 What Can You Do?

1. Be clear and direct.

- Introduce yourself and explain what you are doing.
- Do this every time, so the person you care for isn't confused or upset.
- Talk directly to the person you care for.
- Make eye contact.
- Do not talk with other people in the room about the person with dementia.

2. Create a welcoming environment.

- Be respectful and sensitive.

If the person you care for feels embarrassed, they might not ask questions or ask for help. Remember people can read and feel emotions.

- Be patient.

The person you care for will need more time to complete tasks, finish what they are saying, or respond to you.

- Avoid saying, "Don't you remember? We just talked about that!"

Comments like this make people more frustrated and embarrassed. If your loved one is asking a question, answer the question. To them it's the first time asking

When you feel frustrated, try to remember it's the disease, not the person.
For example: Mom was not bad, the dementia was bad today.



3. Prepare for appointments.

- Write a list of questions and things you want to talk about.
- Help the doctor prepare. Before the appointment, send:
Questions and changes or new behaviors you are worried about
- Use “I” statements instead of “you” statements when you talk with health care providers.
For example, instead of saying, “YOU said these medications would help his mood swings,” say, “I am concerned that the medication is not helping his mood.”
- Before you leave, review what you talked about with the doctor.
(We talk more about teach-back on page 14.)
- If you can’t go to an appointment with the person you care for, ask someone else to go.
Give them a list of questions and things to talk about.
Ask them to take notes and write down answers to all questions.

Preparing to speak with a doctor video.

What questions can you prepare for the doctor?

4. Use plain, simple language.

- Use words with 1 or 2 syllables.

Say: use

Don't say: utilize

- Use simple sentences, with one idea per sentence.

Say: You have a doctor's appointment at 3:00 tomorrow. We can ask if you need a medication refill then.

Don't say: We can ask the doctor about your medication when we go to your appointment tomorrow afternoon then we'll know if we should order a refill.



- Don't use jargon or acronyms.

Say: "Do you feel dizzy or lost?"

Don't say: "Do you feel disoriented?"

- Give specific instructions.

Say: We need to give Mom her medicine at 2:00 pm.

Don't say: We need to give Mom her medicine in the afternoon.

- Don't use slang.

Say: It's time to go to the store. Please get in the car.

Don't say: Jump in the car. It's time to go.

- Name the objects instead of saying "it" or "that."

Say: Here is your pill.

Don't say: Here it is.

- Use active voice, not passive voice:

Say: The doctor will ask about your medical history. Can we make a list of your history together?

Don't say: You will be asked to give information about your medical history, so you should be prepared.

- Think of ways to simplify.

Instead of saying...	Say this...
Cognitive	"how the brain works"
Cautiously	"with care" or "slowly"
Prognosis	"what will likely happen because of a sickness"
Alzheimer's Disease	"A disease of the brain that causes people to forget things"
Adverse	"bad"
Depression	"sad" or "unhappy"
Disorientation	"Losing sense of time, direction or recognition"
Medicare	Health care insurance for people age 65 and over or certain people on social security disability
Medicaid	Health care insurance for certain people with lower income

- Turn questions into answers by saying the solution not the question.
 - Say:** Here is a glass of water.
 - Don't say:** Are you thirsty?
- Turn negatives into positives.
 - Say:** Let's walk to the living room.
 - Don't say:** You are going the wrong way.

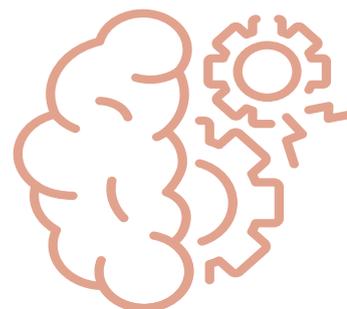
- **Do the math for family members and people with dementia.**
For example: If their appointment costs \$100 and there is a 20% co-pay, tell them they need to pay \$20.
- **Be careful with numbers.**
 1. Use frequency (1 out of 10) instead of percent (10%).

5. Slow down.

- **Speak clearly and slowly.**
- **Pause at the end of sentences and before changing topics.**

6. Reinforce your words with pictures.

- **Show pictures when you explain a concept.**
- **Use pictures that clearly explain your message.**



Which picture is better to use when talking about eating healthy foods?



7. Don't give too much information.

- Give only 2 - 3 "need to know" pieces of information at a time.
- Do not overwhelm with all the details. This can cause anxiety.
- Present information in chunks.
 - Share one idea first.
 - Pause to make sure the person you care for understood.
 - Then, present the second idea.
- Use words and comparisons that are meaningful to the person you care for. For example, if they call movies "flicks," use that term to introduce a patient education video.

8. Encourage questions

- Family members might have a lot of questions. Their loved one will not.
- Talk with them in a way that encourages questions.
 - Say:** It's question time now, tell me your questions.
 - Don't say:** Do you have any questions?

9. Check understanding using "Teach-Back"

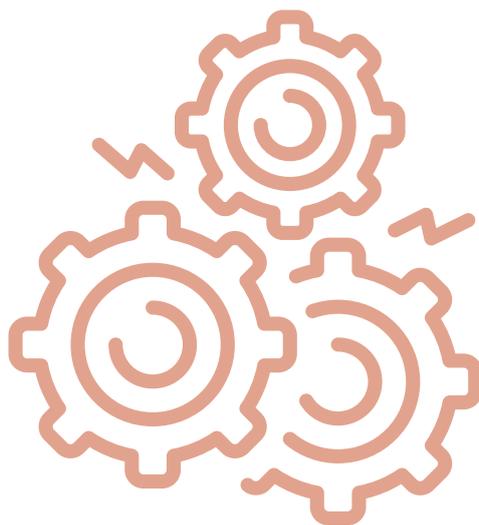
- Teach-back is a non-judgmental way to check understanding.
 - It is NOT meant to "quiz" a person.
 - Instead, teach-back helps you know if you did a good job explaining.
- Teach-back is very helpful when talking about medicine.
- If teach-back shows a misunderstanding, re-explain in a different way and do teach-back again.

You can say:

- “I know this is your first inhaler and the doctor gave a lot of instructions. Can you show me how you will use it?”
- “I know Mom has a lot of new medicine. What pills will you give her tomorrow morning when you’re with her?”
- “The pharmacist gave us a lot of information about your new medicine. What will you Dad about the side effects?”
- “The doctor went over a lot of information today. The new medicine sounds like it will be helpful. What food do you think we should get at the store to help you take it?”

Remember:

- Teach-back and other communication strategies are helpful for people with mild cognitive impairment.
- The strategies might not help people with advanced dementia.
- Use these strategies to improve communication with other caregivers and family members.
- Use teach-back with a provider, to make sure you understood. You can say, “we talked about a lot of things and I want to make sure I understood what you said...”



How can you help the people you care for with memory?

1. Use written instructions to support the instructions you talk about.

- Make sure the instructions are easy to see and read.
- Talk through the written instructions together.

2. Learn what part of the day works best for the person you care for.

- People with dementia often learn new habits better during specific parts of the day.
- Sometimes the morning is better because they are well rested.
Sun-downing can happen at the end of the day.
Sun-downing is when a person gets agitated easily, feels depressed, and does not want to do anything.
- For some people, mornings are difficult and evenings are a better time.



3. Find strategies to help when the person you care for becomes frustrated or upset.

- Here are some strategies you can try:
- Stand or sit in front of them, at eye level, and maintain eye contact.
- Use “us” and “we” instead of “you.”
 - Say:** “Why don’t WE look at the checkbook together.”
 - Don’t say:** “YOU messed up the checkbook, because YOU didn’t listen.”
- Talk in a calm manner.
- Use physical touch.
- Be aware of your body language.
- Set up a routine.
- Put music on to help everyone relax.
 - Try “Connecting Through Music” from Teepa Snow:
<https://youtu.be/m-lckAgnVQw>
- Use very simple language.
- Limit explanations to avoid frustration.
- Be direct and say what to do. Do not ask them to do something or ask questions.
- Take self-care breaks for yourself.
- Walk away and take a short timeout. Then start over again.
- Ask for support - know who you can call if you need help.

Part 3 Special Health Literacy Considerations

Refugee and Immigrant Populations: Cultural Considerations

Things to consider:

- beliefs about medicine and healing practices
- caregiving roles through end of life
- past trauma experiences
- not familiar with healthcare system

Refugee and Immigrant Populations: Language Considerations

Things to consider:

- level of education
- native language and if able to understand and speak English
- use of interpreters to help with translations

What else should you consider?

Sometimes the word “Alzheimer’s” can be difficult for a person to hear. If the person you care for becomes upset with the word “Alzheimer’s,” try saying something like “memory trouble” instead.

People with dementia can have behaviors or say comments that hurt the people who care for them. Try to remember, it is the disease “talking,” not the person you care for. You might have to remind other family, caregivers, and friends.

Remember that people with Alzheimer’s disease or other dementias may not always remember what you said, but they will remember how you made them feel. Emotions are often the last to be forgotten, if at all.

Facial expressions, tone of voice, and body language are all important forms of communication. Learn to understand these non-verbal communication cues of the person you care for. Remember, also, that the person you care for will notice your non-verbal communication cues, especially if you are frustrated.

You are not alone.

- More than 6 million Americans have Alzheimer’s.
- Over 11 million American’s provide unpaid care for people with Alzheimer’s and other dementia.

It is always important to take care of yourself, and even more so when you are helping take care of another person. Stress, burnout, fears, and tears are real.

There is support to help you.

Family Caregiver Support from Greater Wisconsin Agency on Aging Resources, Inc.:
<https://gwaar.org/family-caregiver-support-for-professionals>

Part 4 Resources

Alzheimer's Association www.alz.org. 24-7 Helpline: 1-800-272-3900

Alzheimer's & Dementia Alliance of Wisconsin www.alzwisc.org. Phone: 1-608-232-3400
(In Wisconsin toll free at 1-888-308-6251). Email: support@alzwisc.org

Alzheimer's Disease Education and Referral (ADEAR) Center www.nia.nih.gov/alzheimers.
Phone: 1-800-438-4380. Email: adear@nia.nih.gov

Alzheimer's Foundation of America www.alzfdn.org, Phone: 1-866-232-8484. Email: info@alzfdn.org

Association for Frontotemporal Degeneration www.theaftd.org. Phone 1-866-507-7222 (toll-free)

Centers for Disease Control and Prevention (Alzheimer's Disease) www.cdc.gov/aging/aginginfo/alzheimers.htm. Phone: 1-800-232-4636

Eldercare Locator (information about community resources, such as home care, adult day care, and nursing homes) www.eldercare.gov. Phone: 1-800-677-1116

Family Caregiver Alliance www.caregiver.org. Phone: 1-800-445-8106 (toll-free). Email: info@caregiver.org

Family Caregivers Rock www.familycaregiversrock.org

Healthy Aging in Rural Towns (HeART) www.care.nursing.wisc.edu/heart/

Lewy Body Dementia Association www.lbda.org. Phone 1-800-539-9767 (toll-free LBD Caregiver Link)
1-404-935-6444 (national office). Email: lbda@lbda.org

National Institute on Aging Information Center www.nia.nih.gov. Email: niaic@nia.nih.gov

Parkinson's Foundation www.parkinson.org. Phone: 1-800-473-4636 (toll-free).
Email: contact@parkinson.org

UW Madison Institute on Aging www.aging.wisc.edu/external/index.php. Phone: 608-262-1818

Wisconsin Alzheimer's Institute www.wai.wisc.edu. Phone: 608-263-2862

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Greater Wisconsin Area on Aging Resources



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Looking for a reference from this toolkit?

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