



Improving Alzheimer's Disease and other Dementia Care through Health Literacy



wisconsin
**health
literacy**

Table of contents

What is this toolkit and whom is it for?	3
Part 1: Literacy and Health Literacy	4-6
What is health literacy?	
What is the impact of low health literacy?	
Who is at risk for low health literacy?	
The benefits of improved health literacy for independence	
Increased safety – more effective use of medication	
Part 2: What Can You Do? Improved Health Literacy for Better Communication	7-12
Introduce yourself and explain what you are doing	
Create a welcoming environment	
Practice plain, simple language	
Slow down	
Support words with pictures that reinforce the message	
Limit the amount of information provided	
Encourage questions	
Verify understanding using “Teach-Back”	
Identify ways to help memory	
Part 3: Special Health Literacy Considerations	13-14
Refugee and immigrant populations: Cultural considerations	
Refugee and immigrant populations: Language considerations	
Things to consider for everyone with dementia	
Part 4: References	15
Part 5: Resources	15

What is this toolkit and whom is it for?

This toolkit has been created to help improve the health, health care and caregiving for those with early Alzheimer's disease and other forms of dementia through improved health literacy. It is designed to inform caregivers, health care workers, health educators, case workers, personal care representatives, family members and others about health literacy principles and techniques that can be used to improve communications and enhance care for those in the early stages of dementia.

Dementia is a general term that describes a wide range of symptoms associated with a decline in memory or other thinking skills that is severe enough to reduce a person's ability to perform everyday activities.¹ Alzheimer's disease, the most common form of dementia, is named after Dr. Alois Alzheimer who in 1906, examined the brain tissue of one of his deceased patients who had symptoms of the disease.²

The statistics relating to the number of people who have or will have Alzheimer's disease are staggering. In 2017, it is estimated that approximately 5.5 million Americans are living with Alzheimer's disease.³

Many American adults struggle with health literacy. This toolkit is intended to raise awareness of the issues faced by people receiving health information and provide some practical methods to improve communication by people providing health information. Only 12% of American adults are proficient in health literacy and for seniors it's only 3%.⁴

Seniors are at risk for lower health literacy for many reasons. For example, physical, psychological and cognitive changes occur with aging, all of which have the potential to limit health literacy. Those with dementia are especially at risk and this toolkit details how improved health literacy can uniquely benefit those individuals. Although there is no known cure for Alzheimer's disease, active medical management can improve the quality of life for those individuals and their caregivers.⁵ Better health literacy is an essential aspect of this improvement.

Part 1: Literacy and Health Literacy

Literacy skills are the strongest predictor of health status, more than age, income, employment status, education level or racial/ethnic group.⁶

What is health literacy?

There are two sides to health literacy: 1) The ability of the person receiving health information to access, understand and use that health information. 2) The ability of the person communicating health information to effectively achieve understanding. For example, persons with low health literacy might find it hard to understand printed health information, what their provider tells them during a visit, how to take care of their health, how to take medications, or how to use their health insurance. They may have difficulty making health decisions or knowing what health information is reliable. Likewise, a caregiver or healthcare provider may not clearly communicate health information in a way that a patient can access, understand, or use to improve health.

The National Assessment of Adult Literacy (NAAL) study revealed that only 12% of the U.S. adult population have proficient health literacy. Again, for those ages 65 and older only 3% are proficient. What does that mean? As an example, only 3 out of 100 seniors can evaluate information to determine which legal document is applicable to a specific health care situation.

Furthermore, nearly 60 out of 100 seniors have Basic or Below Basic health literacy. For example, someone who has below basic health literacy is able to circle the appointment date on a hospital appointment slip, and not much more.⁴

Those with low health literacy may have trouble with the following:

- Locating health services
- Filling out forms
- Sharing medical history
- Managing chronic health conditions
- Understanding directions on medication labels

What is the impact of low health literacy?

1. Poorer health knowledge
2. Poorer health status
3. Higher mortality
4. Increased hospital use
5. Increased Emergency Department use
6. Increased health care costs
7. More likely to skip preventive measures, including mammograms, pap smears and flu shots
8. Less likely to participate in preventive services such as tobacco cessation and obesity prevention programs

Who is at risk for low health literacy?

Almost everyone will have difficulty with health literacy at some point. Illnesses, stress, lack of sleep, and medication use all have the potential to affect one's level of health literacy.

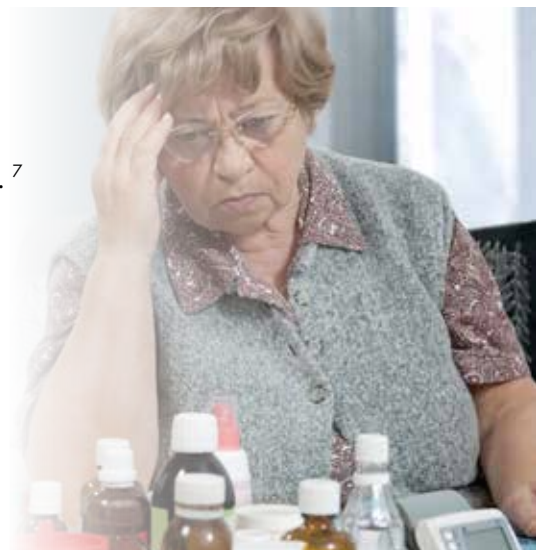
But seniors are especially at risk. Why?

Some of the factors for lower levels of health literacy are as follows:

- Seniors have decreased reading skills. 45% read at the lowest reading level.⁷
- Physical changes such as decreased hearing, vision or the body's ability to metabolize medicine.
- Psychological changes such as increased depression and anxiety.
- Cognitive changes also occur. It may take longer to process and understand information and many seniors have trouble with short term memory loss.

And consider this:

- Seniors have more chronic illnesses and use more medical services than other adults.⁸
- Approximately 85% of older adults have at least one chronic condition that must be managed.⁹
- Seniors take more medicine, which can increase the chance of an adverse drug event, whether due to risk of interactions, complicated dosage schedules or difficulty in reading and understanding labels.



The benefits of improved health literacy for independence

Many physical and cognitive changes can be normal for people as they age. However, when these changes start to impact a person's work life, social life and daily life, this is NOT a normal part of aging.¹⁰

Improved health literacy can increase the chances of remaining independent and/or staying in one's current living situation longer. The more individuals know about dementia, the better they can prepare, whether for their health, family or finances.



Increased safety – more effective use of medication

Health literacy can also help improve the effective and safe use of medications. Following dosage instructions can be very difficult, especially if one takes multiple medications and/or if cognitive abilities are compromised. This can lead to serious problems, including adverse drug events and even death. There are ways to help improve medication adherence:

- Seek a pharmacy consultation. Medicare, Medicaid and some private insurance companies will pay for part or all of the cost to speak one-on-one with a pharmacist either in-person or over the phone to review medications. This may help simplify the number of medications taken and/or the dosage schedule. A trusted friend or family member should accompany an individual with dementia to the appointment.
- Ask the pharmacist or doctor questions about a particular medicine at any time. This could be in person when picking up a prescription, during a pharmacy consultation or at the doctor's office. Individuals can also call and speak to the pharmacist, doctor or staff with questions.
- Use a pill box. This can be an effective way of helping to remember when to take which medication.
- Use a written medication list. Adding pictures of the medication that show the shape, size and color of the pill can also be helpful for those with dementia.

CAUTION: Sometimes there will be a new manufacturer that the pharmacy is buying from, so the pill color, size and/or shape may change from one refill to the next, causing confusion. It is important that patients take a list of their medication to the pharmacy to make sure there have been no such changes.

Part 2: What Can You Do? Improved Health Literacy for Better Communication

Improving communications and understanding of health information is beneficial for everyone, no matter their health literacy level. The following health literacy techniques are therefore useful to all, but can be especially beneficial for those in the early stages of dementia.

1 Introduce yourself and explain what you are doing:

Do this every time. If you don't, the individual may become upset or confused, making communication and understanding more difficult. (Note: Needing to introduce yourself may be more important once the individual has advanced beyond the early stages of dementia.) If the individual with dementia comes to an appointment with a caregiver, friend or family member, be sure to make eye contact and talk directly with the individual. In other words, do not talk with others in the room as though the person with dementia is not there.

2 Create a welcoming environment:

Often people feel embarrassed when they don't understand health information and therefore do not want to ask their questions or seek the additional help they need. Health care providers, professionals and caregivers can help create a more welcoming environment by doing the following:¹¹

- Help prepare the individual for their various appointments by offering tips on what questions to ask and what to bring to the appointment. Caregivers, family members or even a trusted friend should go with the individual to the appointment to help write information down and record what was said.
- Exhibit an attitude of helpfulness, respect, caring and sensitivity to feelings so that the individual feels comfortable at the appointment.
- Health care providers and professionals should offer help to both the individual with dementia and to their caregivers, family or friends in completing health forms and other information. Provide a comfortable setting in which to do so.
- Provide individuals with information they need to make the best decision, but do so in a manner that reassures them that many others have the same problem understanding health information because it's complex. Encourage questions in a non-judgmental and caring manner.
- Remember that even those with good literacy skills and no memory decline prefer simple, understandable health information.
- Avoid saying things like, "Don't you remember? We just talked about that!" This will increase frustration and make the person feel embarrassed that he or she could not remember.

3 Practice plain, simple language:

- Use words with 1 or 2 syllables, such as “use” not “utilize.”
- Use simple sentences, especially those that just have one idea. Example:
NO: Help may be available for you to pay your medical bills and to find out if you qualify, here’s what you should do.
YES: We may be able to help you pay your medical bills. Find out if you qualify. Follow these steps.
- Avoid jargon and acronyms: People are afraid to ask what you mean because they do not want to feel embarrassed that they do not understand.
- Use specific instructions:
NO: Get adequate rest.
YES: Get at least 7 hours of sleep each night.
- Avoid using slang:
NO: Jump in the car. It’s time to go.
YES: It’s time to go to the store. Please get in the car.
- Name the objects instead of using “it” or “that.”
NO: Here it is.
YES: Here is your shirt.
- Use active voice rather than passive voice:
Passive: You will be asked to give information about your medical history.
Active: We will ask for information about your medical history.

- Think of ways to say things in simpler terms.

Instead of saying...	Say this...
Cognitive	"how your 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 providing the solution rather than the question.
NO: Are you thirsty?
YES: Here is the water fountain.
- Turn negatives into positives:
NO: Don't walk that way.
YES: Let's walk this way.
- A word about numbers:
 1. Do the math for those with dementia. For example, if their appointment cost \$100 and there is a 20% co-pay, inform them that their out-of-pocket cost is \$20.
 2. Keep denominator the same; use: 5 out of 100 compared to 10 out of 100
 3. Use frequency (1 out of 10) instead of percent (10%)
 4. Use comparisons/analogies, such as your tumor is the size of a lemon.

4 Slow down:

- Speak clearly at a moderate pace. Understanding drops dramatically with faster speech and people are reluctant to ask you to repeat what you said for fear of embarrassment.

5 Support words with pictures that reinforce the message:

- Show pictures while you explain a concept. This is beneficial for everyone, whether it is a person with no memory loss or one who has dementia. But as the dementia progresses, pictures become even more relevant. Be sure the pictures support the message you are trying to send. For example, if you are discussing the importance of healthy foods, the picture on the left better reinforces that message.



6 Limit the amount of information provided:

- Focus on giving only “need to know” concepts. Do not overwhelm individuals with dementia with every little detail.
- Chunking: Break material into chunks and limit the amount of information to 2-3 pieces at a time, maybe even fewer, depending on the individual.
- Use analogies or words that are particularly relevant to the individual with dementia. For example, if they referred to movies as “flicks” then use that term while talking with them.

7 Encourage questions:

- There will likely be many questions that those with dementia – or their caregivers – may be hesitant to ask, or they may have trouble doing so. Talk with them in a way that encourages questions.
 - o NO: Do you have any questions?
 - Individuals with dementia may often feel put on the spot with this question and will usually just say “no” even if they do have questions.
 - o YES: It’s question time now. Please share your questions.

NOTE: A caregiver, family member, or friend should go to a health care or other appointment with the individual with dementia to help write down information and record what was said. It is helpful to bring a list of questions to the appointment. If the caregiver, family member, or friend has concerns about changes or behaviors they are seeing in the individual, they should send that information ahead of time to the provider. This is more respectful than sharing this information in front of the individual at the appointment, as it may cause agitation or anxiety.

8 Verify understanding using “Teach-Back”:

- Ask the individual in a non-judgmental way to demonstrate understanding. This is NOT meant to “quiz” the person, but rather to make sure you are doing a good job of explaining things. This can be particularly helpful with medication use.

You can ask:

- “We have gone over a lot of things relating to your medicine. To make sure I did a good job of explaining all this to you, please show me how you will use your inhaler when you get home.”
- If teach-back shows a misunderstanding, try to re-explain in a different way.

A WORD OF CAUTION: Although the teach-back method and other clear health communication and reinforcement strategies may help those with mild cognitive impairment, patients with advanced dementia are not likely to benefit.

However, these communication strategies should also be directed to caregivers, many of whom may have lower health literacy as well.¹²

REMEMBER: The teach-back method can also be used to help identify and assess one’s cognitive abilities.

Identify ways to help memory

1. Use written instructions to help reinforce verbal instructions. When doing so, however, be sure to check that the individual can read and see the instructions, as well as understand them. It may also be helpful then to talk through the written instructions together.
2. People with early dementia are often better at forming new memories during certain parts of the day – sometimes in the morning after being well rested. But for others, mornings are difficult and evenings are a better time for them. Try to find their better times for new instructions or repetition of instructions.
3. Repetition of instructions and activities over a period of time can help form new memories and habits.
4. Engage the individual in figuring out how to create a new habit. For example, somebody may need to take new medication each morning. You can help them determine how they will work taking their medication into their morning routine. It takes several weeks to develop a new habit for people without cognitive decline, so expect that it will take longer for those with memory problems. Help them develop a plan and keep checking to see how well it is working and repeat the instructions if necessary.



Part 3: Special Health Literacy Considerations

Refugee and immigrant populations: Cultural considerations

As with other medical conditions, Alzheimer's disease and other forms of dementia are understood, treated and cared for differently in various cultures. Gaining as much knowledge as possible about individuals' language, culture and background is very important, as this could affect how they perceive, process, understand and act upon medical information.

Understanding such things as caregiving roles, gender and elder roles, literacy levels, cultural adaptation, and cultural beliefs about western medications compared to traditional healing practices, can all affect the person's medical care. For example, in some cultures the family members take care of the individual through the end of life, and would not consider a nursing home or paid caregiver. In more patriarchal cultures, males may need to be included for decision-making regarding treatment and care.



It is also important to remember that some refugee and immigrants have suffered great trauma, serious losses and/or were living in extreme poverty and unrest before coming here, all of which could affect care and treatment.¹³

Adding to all the above, the American health care system may be confusing to them and/or they are now taking unfamiliar medications. Do your best to help them navigate these issues. You may need to take an extra step to explain to them that they must first see a doctor before they can get a prescription medicine, or that the medicines they are taking in their home country could interact with the prescription medicines they are taking here.

Refugee and immigrant populations: Language considerations

Using interpreters whenever there is a language barrier is very important, of course. However, there are times when there is no equivalent word or phrase in another language, or there is a stigma associated with the word “dementia” so describing the symptoms, treatment or care becomes very important.¹³

Levels of education and understanding English can vary greatly from one individual to the next and from culture-to-culture. Some refugees and immigrants have advanced degrees, while others have had little or no formal education. Some may be fluent in English while many are not. And still some cannot read or write in their first language. You may not be able to tell who can read or write, so if you have translated materials, you should still provide those to the individual. You can reduce any embarrassment individuals may feel about not being able to read and write by letting them know they can take this home with them to share with friends and family members.

In addition to using interpreters, it is also important to use a demonstration whenever possible, such as showing someone how to use a particular medication. Drawing or using culturally relevant pictures can also be a useful way to help with the language barrier.

Things to consider for everyone with dementia

- Use “We” statements instead of “You” when talking with individuals with dementia. For example, instead of saying, “YOU aren’t listening to me!” or “YOU really messed up this checkbook,” instead use “We” as in “Why don’t WE take a look at the checkbook together.”
- Sometimes as a diagnosis or in a discussion, the word “Alzheimer’s” can be really harsh to hear and may have a negative effect on somebody. If so, soften that word. When you know somebody personally, you can understand better what they may be able to handle. Perhaps you could use “memory trouble” or something similar that may be less harsh.
- It is helpful for caregivers, family members or friends to use “I” statements instead of “You” when talking with health care providers. For example, instead of saying, “YOU said these medications would help with his mood swings,” say, “I am concerned that the medication is not helping his mood.”
- It is important for caregivers, family members and friends to understand that sometimes they will see behaviors or hear comments from those with dementia that are hurtful or concerning. It is important to remember that it is the disease “talking” and not the individual.
- Keep in mind that facial expressions, tone of voice, and body language are all forms of communication for you, as well as with the individual with dementia. Learn to understand those non-verbal communications from the individual with dementia.

Remember that those 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.

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PART 5: Resources

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

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

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

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

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

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

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

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

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

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

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

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

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

Wisconsin Department of Health Services: Dementia Care Specialist Program (embedded within select Aging and Disability Resources Center – ADRCs) Website: www.dhs.wisconsin.gov/adrc/dementia-care-specialist-program.htm

The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer's Disease, Related Dementias, and Memory Loss, by Nancy L. Mace, M.A. and Peter V. Rabins, MD, MPH

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