Dementia: What You Should Know

Dementia is not a specific disease. It's an overall term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities. Alzheimer’s disease is the most common type of dementia and accounts for 60 to 80 percent of cases. Other types of dementia include Dementia with Lewy Bodies, Frontotemporal, and Vascular.

What is Dementia Friends?

Dementia Friends is a global movement developed by the Alzheimer’s Society in the United Kingdom and now underway in the United States.

The goal is to help everyone in a community understand five key messages about dementia, how it affects people, and how we each can make a difference in the lives of people living with the disease.

People with dementia need to be understood and supported in their communities. You can help by becoming a Dementia Friend.
## Normal Aging vs. Alzheimer’s Disease & Related Dementia’s

<table>
<thead>
<tr>
<th>Normal Aging</th>
<th>10 Early Signs and Symptoms</th>
</tr>
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<tbody>
<tr>
<td>Sometimes forgetting names or appointments but remembering them later</td>
<td>Memory loss that disrupts daily life</td>
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<td>Making occasional errors when balancing a checkbook</td>
<td>Challenges in planning or solving problems</td>
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<tr>
<td>Needing occasional help to use the settings on a microwave or to record a TV show</td>
<td>Difficulty completing familiar tasks at home, at work or at leisure</td>
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<tr>
<td>Confused about the day of the week but recalling it later</td>
<td>Confusion with time or place</td>
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<tr>
<td>Vision changes related to cataracts</td>
<td>Trouble understanding visual images and spatial relationships</td>
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<td>Sometimes having trouble finding the right word</td>
<td>New problems with words in speaking or writing</td>
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<tr>
<td>Misplacing things from time to time and retracing steps to find them</td>
<td>Misplacing things and losing the ability to retrace steps</td>
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<tr>
<td>Making a bad decision once in a while</td>
<td>Decreased or poor judgment</td>
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<tr>
<td>Sometimes feeling weary of work, family and social obligations</td>
<td>Withdrawal from work or social activities</td>
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<tr>
<td>Developing very specific ways of doing things and becoming irritable when a routine is disrupted</td>
<td>Changes in mood and personality</td>
</tr>
</tbody>
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**Source:** 10 Early Signs and Symptoms of Alzheimer’s & Related Dementia’s
[www.alz.org/10-signs-symptoms-alzheimers-dementia.asp](http://www.alz.org/10-signs-symptoms-alzheimers-dementia.asp)
**Broken Sentences Worksheet**

Match the sentences in Column 1 to Column 2 by writing your response in the “Answer” column. You should end up with five sentences that make sense and highlight five key messages about dementia!

<table>
<thead>
<tr>
<th>Answer</th>
<th>Column 1</th>
<th>Column 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>______</td>
<td>1. Dementia is not ...</td>
<td>a) ... diseases of the brain. The most common is Alzheimer’s.</td>
</tr>
<tr>
<td>______</td>
<td>2. Dementia is caused by ...</td>
<td>b) ... a normal part of aging. Not everyone who grows old will develop dementia.</td>
</tr>
<tr>
<td>______</td>
<td>3. Dementia is not just ...</td>
<td>c) ... good quality of life with dementia.</td>
</tr>
<tr>
<td>______</td>
<td>4. It is possible to have a ...</td>
<td>d) ... the dementia. People with dementia are a valuable part of the community.</td>
</tr>
<tr>
<td>______</td>
<td>5. There’s more to the person than ...</td>
<td>e) ... about having memory problems. It can affect thinking, communication and doing everyday tasks.</td>
</tr>
</tbody>
</table>
Family Caregivers and Dementia: The Other Silent Epidemic

As the number of those with Alzheimer’s disease and other related dementia increases each year, so does the number of family caregivers who provide the unrelenting care their loved one with dementia needs. In fact, the burden of families caring for their loved one is an epidemic in itself, with 15 million Americans in 2019 providing 18.5 billion hours of unpaid care for loved ones with dementia, equating to a value of $234 billion. Dementia Friendly communities are about the caregiver as much as the person with dementia, so in your efforts please keep in mind the following caregiver data derived from the Center for Disease Control, Alzheimer’s Association, and National Center on Care Giving:

- 80% of people with dementia are cared for in their homes
- Family caregivers caring for those with dementia provide care for a longer duration than caregivers of any other conditions
- Family caregivers for Alzheimer’s disease and other related dementias have an increased risk for anxiety, depression, and poor quality of life than family caregivers of other any other conditions
- 1 in 6 millennials are caring for someone with dementia and report mental, physical, and financial hardships as a consequence of their care giving role
- Studies show family caregivers of those with dementia have diminished immune systems, leading to frequent infection and increased risk of cancers, with evidence of a 23% average increase in stress hormones and a 15% decrease in antibody response
- Spousal caregivers of individuals with dementia aged 66 to 96 have a 63% increase in mortality rates than non-caregivers of those with dementia in the same age range, often times resulting in the passing of the caregiver before the person in which they are providing care!

According to the Family Caregiver Alliance, a subset of the National Center on Care Giving, family care giving for someone with dementia is quickly becoming a public health issue. As a Dementia Friend in Indiana, you have the opportunity to make a difference. Whether it involves reaching out to someone you know who is caring for someone with dementia, leading social change to reduce the stigma, or spreading awareness about the rising challenges facing caregivers of those with dementia, you can make a difference. Connect your family, friends, and your community to Dementia Friends Indiana today!
Bookcase Story

Imagine a 70-year-old woman who has dementia. Now imagine there is a full bookcase beside her. Each book inside the bookcase represents one of her skills or memories.

On the top shelves are her memories of facts and her skill for thinking in complex or complicated ways. For people with dementia, the top or outer part of the brain is damaged first. Skills like math, using language and keeping one’s behavior in check are in this part of the brain. In our bookcase story, these skills are also books on the top shelves.

When dementia rocks the woman’s bookcase, the books on the top shelf begin to fall out. The woman may not remember what she ate for breakfast, or that she has to pay for items at the drugstore or that someone came to visit this morning.

Emotions and feelings are lower down within the bookcase just like they are in the lower or inner part of the brain. This is the instinct area of the brain.

Feelings like love, happiness, frustration and sensing respect reside here. As dementia continues to rock her bookcase, the books on these lower shelves stay for a much longer time.

The bookcase story helps explain different thinking skills and memories and the effects of dementia. Facts and complex thinking will fall away quickly. Emotions and feelings will remain longer.
Everyday Tasks

Write a step-by-step instruction list to complete a task you do daily or often. Make sure someone reading your list could follow the instructions successfully to complete the task.
Communication

Consider these tips when communicating with a person with dementia.

Treat the person with dignity and respect. Avoid talking past the person as if he or she isn’t there.

Be aware of your feelings. Your tone of voice may communicate your attitude. Use positive, friendly facial expressions.

Be patient and supportive. Let the person know that you are listening and trying to understand. Show that you care about what he or she is saying and be careful not to interrupt.

Offer comfort and reassurance. If he or she is having trouble communicating, reassure them that it’s okay and encourage the person to continue.

Avoid criticizing or correcting. Don’t tell the person what he or she is saying is incorrect. Instead, listen and try to find the meaning in what is being said.

Avoid arguing. If the person says something you don’t agree with, let it be. Arguing usually only makes things worse and often increases agitation for the person with dementia.

Offer a guess. If the person uses the wrong word or cannot find a word, try guessing the right word. If you understand what the person means, finding the right word may not be necessary.

Encourage nonverbal communication. If you don’t understand what is being said, ask the person to point or gesture.
**Conversation Tips**

When approaching the person with dementia and starting a conversation:
- Come from the front, identify yourself, and keep good eye contact. If the person is seated or reclined, go down to that level.
- Call the person by their preferred name to get his or her attention.
- Use short, simple phrases and repeat information as needed. Ask one question at a time.
- Speak slowly and clearly. Use a gentle and relaxed tone.
- Patiently wait for a response while the person takes time to process what you said.

During the conversation:
- Provide a statement rather than ask a question. For example, say “The bathroom is right here,” instead of asking, “Do you need to use the bathroom?”
- Avoid confusing and vague statements about something you want the person to do. Instead, speak directly: “Please come here. Your shower is ready.” Name an object or place. For example, rather than “Here it is,” say “Here is your hat.”
- Turn negatives into positives. Instead of saying, “Don't go there,” say, “Let’s go here.”
- Give visual cues. Point or touch the item you want the person to use or begin the task for him or her.
- Avoid quizzing. Reminiscing may be healthy, but avoid asking, “Do you remember when?”
- Try using written notes or pictures as reminders if the person is able to understand them.
Five Key Messages

- Dementia is not a normal part of aging. Not everyone who grows old will develop dementia.
- Dementia is caused by diseases of the brain. The most common is Alzheimer’s.
- Dementia is not just about having memory problems. It can affect thinking, communication and doing everyday tasks.
- It is possible to have a good quality of life with dementia.
- There’s more to the person than the dementia. People with dementia are a valuable part of the community.

Turn Your Understanding into Action
As a Dementia Friend, I will... (select at least one)

- Get in touch and stay in touch with someone I know living with dementia
- Support dementia friendly efforts in my community
- Start a dementia friendly effort in my community
- Volunteer for an organization that helps people with dementia
- Campaign for change, e.g. by participating in local advocacy events or contacting government officials
- Encourage local businesses and other organizations to become dementia friends
- Encourage family members and friends to become Dementia Friends by attending info sessions or viewing videos at www.dementiafriendsindiana.org
- Carry out a personal action e.g. being more patient when out in my community
- Volunteer to participate in a clinical trial
- Adopt one or more dementia friendly practices in my personal and/or professional life
- Like Dementia Friends Indiana on social media (Facebook, Instagram, LinkedIn, and Twitter)
Resources in Your Community

alzheimer's association

Greater Indiana Chapter

www.alz.org

800.272.3900

www.cicoa.org

317.803.6131

www.dementiafriendsindiana.org

Dementia Friends Indiana, a Dementia Friendly America initiative, is administered in the state of Indiana by CICOA Aging & In-Home Solutions.
Specialized residential options offering memory loss supports and services

Dementia-aware and responsive legal and financial planning

Welcoming and engaging communities of faith

Dementia-aware and responsive banking practices

Transportation, housing, and public spaces

Understanding and supportive neighbors and community members

Dementia-informed local government emergency planning and first response

Options that maximize independent living and sustain meaningful community engagement

Businesses that foster customer service and environments that support customers with dementia and employee caregivers

Health and long term care that promotes early diagnosis and specialized care and support throughout the care continuum