Dementia

The difference between
DEMENTIA AND ALZHEIMER’S

WARNING SIGNS
of Dementia

Coping with
CHALLENGING BEHAVIORS

Tips for family caregivers
CONTENTS

Dementia and What You Need to Know About It ....................... 3

Types of Dementia .................................................................. 4

Causes of Dementia .............................................................. 5
Other Conditions That Can Cause Dementia ......................... 5
Early Signs of Dementia ......................................................... 5

Diagnosing Dementia ............................................................ 6

Treating Dementia ............................................................... 7

After Diagnosis: Discussing Your Wishes ............................... 7

Coping With Challenging Behaviors ...................................... 8
5 Tips for Coping ................................................................. 8

Family Caregivers: Taking Care of Yourself ......................... 9
10 Tips for Family Caregivers ................................................. 9
Impact on Family Caregivers ................................................ 10

Reducing Your Risk ............................................................ 10

Faith & Dementia ............................................................... 11

A Prayer ........................................................................... Back Cover
Dementia and What You Need to Know About It

Everyone knows that we become forgetful as we grow older, right? Wrong.

Memory problems are not a normal part of aging, but it isn’t always easy to know the difference between normal changes that affect us as we grow older and more serious symptoms that might be the sign of real memory problems that we normally associate with dementia.

What is Dementia?
Dementia is the descriptive term for any medical condition that causes memory problems and problems with at least one other brain function, such as speech, concentration, visual perception or more complex thinking involving problem solving, planning and organization.

Two of the most widespread forms of dementia are Alzheimer’s disease, which accounts for 60 to 80 percent of those with dementia, and vascular dementia, which accounts for 20 percent. Today, more than 5 million Americans suffer from Alzheimer’s disease, while millions more are affected by changes in blood circulation in the brain, known as vascular dementia.

In dementia, memory loss is common, especially of recent events and detailed situations. People with a recent diagnosis of dementia will talk about the frustration of not remembering something that happened recently. Family members may notice that their loved one remembers events from long ago more easily than recent events.

In addition to memory loss, another aspect of dementia may be language difficulty. Persons with dementia may have a hard time expressing themselves or struggle with finding the right word to say. They may have a hard time understanding what is being said to them or have difficulty tracking details in conversation. These problems show up in written language, too.

In dementia, complex activities such as planning, organizing and problem-solving can become more challenging. Sometimes doing even simple, routine things in the right order becomes more difficult, like putting on one layer of clothing over another in the wrong way or preparing a meal. Sometimes, family members may notice times of confusion.

Alzheimer’s disease is present in as much as 10 percent of the population over age 65.

In 2017, 5.5 million in the U.S. were estimated to have Alzheimer’s. Because the number of adults over age 65 is expected to nearly triple by 2050, this number is expected to rise to 16 million.

Alzheimer’s is the fifth-leading cause of death for individuals over age 65 and a leading cause of disability and poor health.

- Source: Alzheimer’s Association
Alzheimer’s Disease
Alzheimer’s disease is the most common form of dementia and cannot be reversed. Nerve cells in the brain are damaged or die due to neurofibrillary tangles and amyloid plaques. Neurofibrillary tangles destroy the internal structure of the cell. Amyloid plaques disrupt the ability of brain cells to communicate with each other through the buildup of protein plaques in strategic areas outside the cells.

Although promising research is being done, currently we know of no way to stop or reverse these processes once they have begun. However, a class of medications known as cholinesterase inhibiting drugs (e.g. Aricept, Exelon, and Razadyne) can help brain cells work more efficiently and can help a person function at a higher level for a longer period of time.

Vascular Dementia
Vascular dementia, caused by cerebrovascular disease or stroke, is another common form of dementia. The pattern of vascular dementia can be one of sudden onset of symptoms followed by a period of stable functioning over time, followed by another period of decline in stable functioning. This is sometimes referred to as a stepwise pattern of decline. But vascular changes can also come about gradually. It is also possible that people can have a combination of Alzheimer’s dementia and cerebrovascular disease, which can make diagnosis especially challenging.

In some cases, the same medication used for Alzheimer’s disease can be helpful for people with vascular dementia.

Decline can be minimized by decreasing “vascular risk factors” or health concerns that place someone at a higher risk for further damage to blood vessels in the brain. These include high blood pressure, elevated cholesterol, diabetes, untreated heart disease and smoking.

Dementia Types

<table>
<thead>
<tr>
<th>Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s</td>
<td>60-80%</td>
</tr>
<tr>
<td>Vascular Dementia</td>
<td>10-20%</td>
</tr>
<tr>
<td>Other Dementias</td>
<td>&lt;10%</td>
</tr>
</tbody>
</table>
Causes of Dementia

Dementia is the result of damage to the brain cells which affects communication within the brain cells. Some forms are progressive, meaning they will continue to worsen over time. Other forms are stable. Still others, like those caused by low thyroid or certain vitamin deficiencies, are entirely reversible or treatable. Many other conditions can cause dementia, including head injury, brain tumor, Parkinson’s, and substance abuse. In some cases, untreated depression can mimic symptoms of dementia.

Knowing the cause of a person’s dementia is critical for ensuring the most effective treatment. The earlier the problem is diagnosed, the more likely treatment will be able to stop or reverse symptoms of cognitive decline (as in depression or normal pressure hydrocephalus) or to maximize the brain’s ability to function over time (as in Alzheimer’s disease). Effective management of dementia requires a thorough assessment, accurate diagnosis and prompt treatment.

Other Conditions That Can Cause Dementia

• Head injury
• HIV infection
• Brain tumor
• Normal pressure hydrocephalus (water on the brain)
• Metabolic disorders
• Medications or drug combinations
• Substance abuse
• Parkinson’s disease
• Other brain diseases

Early Signs of Dementia

1. Repeating questions or statements.
2. Forgetting to pay bills or paying them twice.
3. Missing scheduled appointments.
4. Uncharacteristically misplacing items around the house.
5. Changes in mood and personality.
6. Decreased motivation.
7. Uncharacteristically making rude or inappropriate comments.
9. Having problems with complex activities (Example: driving).
10. Becoming more easily confused.
Although there are many exciting treatment possibilities being studied, there is not currently any way to stop or reverse the symptoms in most types of dementia. But because some dementias can be the result of reversible medical conditions, the first phone call should always be to one’s primary care physician to discuss the symptoms.

Medical evaluation begins with a primary care physician who can conduct a thorough health examination and order appropriate laboratory work to rule out a reversible dementia. The physician may also conduct brief screening tests to measure certain cognitive functions, such as an awareness of time and place, learning and memory, language and visual spatial skills. A thorough history of the recent problems described by family is noted. The physician may also order imaging of the brain (e.g. MRI or CT scans).

In some cases, the diagnosis is easy to determine. For example, blood tests can reveal clear evidence of thyroid problems or vitamin deficiencies, which can then be treated with the proper medication. Brain imaging studies can show evidence of strokes, small blood vessel disease or the presence of a tumor. In such cases, treatment could involve medications to reduce the risk of further stroke or blood vessel disease or surgery to remove the tumor.

When these tests do not reveal an obvious cause for the cognitive changes, the physician may recommend neuropsychological assessment—a detailed testing of multiple areas of brain function, conducted by a neuropsychologist. A broad range of brain functions are measured, including intelligence, attention and concentration, higher order cognitive abilities, language skills, motor speed and dexterity, verbal and visual learning and memory and mood. The tests are all painless to complete and are generally done in a question and answer format.

Testing also examines writing, drawing and some simple muscle speed and dexterity tasks. Results can reveal a pattern of cognitive strengths and weaknesses that can help determine the correct diagnosis. For example, people with Alzheimer’s show a certain pattern of memory problems whereas people with vascular dementia may show a different pattern.

**Aging Is the Highest Risk Factor for Alzheimer’s**

1 in 10: People age 65 and older

1 in 3: People age 85 and older

Seek help when:

1. The situation at home becomes dangerous. For example, if adults are unable to prepare meals and do not get enough food.

2. They are forgetting to take important medications.

3. They are unable to keep themselves or their homes clean.
Treating Dementia

Once a diagnosis has been made, the next step is to consider the most appropriate form of treatment. If the condition is determined to be reversible, then the appropriate medication or other medical intervention can and should be started.

Though there is no cure for dementia, treatment with medication can help injured brain cells work more efficiently, while other medications administered later in the process can keep some healthy brain cells from dying. Because treatments are most effective when started early, it’s critical to get an early diagnosis.

Dementia is a complicated and chronic problem. Therefore, it is essential that health care providers communicate with each other and collaborate together in assessment and treatment over time. Since the continuum of care includes outpatient-to-inpatient settings, providers at each stage of the process need to be aware of the “big picture,” and how each member of the treatment team is contributing to care. Team members may include the primary care physician, a hospitalist and psychiatrists as well as multidisciplinary members of the outpatient and inpatient teams (physician, nursing, social work, occupational therapy, physical therapy and discharge planners). Good cooperation and communication among providers will help the person with dementia maintain the highest possible quality of life.

After the Diagnosis: Discussing Your Wishes

Families are encouraged—early on—to be proactive in getting legal counsel for a loved one with dementia. This is especially important because of the irreversible and advancing nature of the illness.

Early planning allows the person with dementia to be involved and express his or her wishes for future care and decisions, eliminating guesswork or disagreement among family members. It also empowers the person with dementia to designate decision makers on his or her behalf. Items to consider include Advanced Directives, Designated Power of Attorney for Healthcare and even guardianship if the loved one cannot give consent for power of attorney, all of which allow trusted family members to assist—and when advanced—to intervene on behalf of a loved one.

Finally, end of life conversations and decisions should take place while a loved one is able to state his or her preferences. This painful but vital aspect of the continuum of care is a real blessing if families know ahead of time how or what their loved one would want when they have a terminal illness and be able to honor those wishes with the help of a palliative care or hospice care team.
Coping With Challenging Behaviors

As Alzheimer’s and other dementias progress, behaviors may change. Challenging behaviors can occur in up to 90 percent of persons with dementia, and can be as upsetting to the person as they are to the caregiver.

As someone’s ability to think, remember or communicate declines, his or her ability to understand and respond appropriately to a situation becomes impaired. This often leads to troublesome behaviors, known as behavioral “acting out,” or what professionals call “need-driven behaviors.”

Need-Driven Behavior
Challenging behaviors can include repetition, resistance, suspicious delusions, confusion, wandering, agitation and verbal or physical aggression. There are often changes in eating and sleeping schedules as well.

Behaviors may lead to erratic, unpredictable and uncontrolled outbursts. However, behaviors have a purpose and are often triggered by unmet needs and the inability to communicate those needs.

Persons with dementia may wander aimlessly. Are they trying to find their children, parents or spouse? Are they agitated because they have a physical complaint and can’t communicate it? Did they become aggressive when a caregiver they no longer recognize is attempting to undress them? Is the room too hot, too cold, too noisy or is a task too overwhelming?

When need-driven behaviors occur in someone with dementia, it is important to try to understand why this is happening. Identifying the triggers may help in offsetting the behaviors and controlling the cascade of events. It is helpful to document what happens before and after the behavior occurs to provide clues to the need being expressed or the goal being pursued. Charting these episodes allows caregivers to actually “see” and track patterns, which can help in developing new approaches and preventing the behavior.

Changing the Behaviors
Once patterns are determined, caregivers can make adjustments in approaches and routines. Strategies to cope with cognitive changes that come with dementia can prevent the chronic stress and loss of control that can lead to challenging behaviors.

Keeping a daily routine can help produce a sense of predictability and security. Increasing socialization, introducing therapies such as music, exercise or pets, making subtle changes to the person’s environment (such as limiting noise and activity), and focusing on the person and not the task, can reduce the likelihood of problematic behaviors. Adjusting expectations to match the capabilities of someone with dementia will also help avoid frustration.

Sudden Changes
Medical illness may be the cause of a marked and rapid decline or sudden onset of behavioral issues in a person with dementia. Often this sudden change, which is called “delirium,” may be due to an easily identifiable and treatable problem such as an uncomplicated urinary tract infection, mild dehydration, pain, constipation, a common cold, a sore throat, itchy skin or lack of sleep. Seek help immediately if you notice a sudden change in a person with dementia.

Five Tips for Coping:
• Try not to take behaviors personally.
• Remain patient and calm.
• Explore pain as a trigger.
• Don’t argue or try to convince.
• Accept behaviors as a reality of the disease and try to work through it.
Family Caregivers: Taking Care of Yourself

Caring for a person with Alzheimer’s disease or dementia is physically, emotionally and financially challenging. The demands of day-to-day care, changing family roles and making difficult decisions on behalf of a family member can be hard to handle.

Taking care of yourself is one of the most important things you can do as a caregiver. A strong support network of family and friends is important to your physical and mental health; if that is not available, consider joining a support group. Continue doing things you enjoy. Consider using adult day care services, or get help from a local home health care agency.

Becoming well-informed about the disease is another important long-term strategy. Search out programs or resources that help you learn about various stages of dementia and Alzheimer’s and about flexible and practical strategies for dealing with difficult situations.

10 Tips for Family Caregivers

1. Seek support from other caregivers. You are not alone.
2. Ask for help when you need it. Accept offers of help and suggest specific things people can do to help you.
3. Take care of your own health so that you can be strong enough to take care of your loved one: maintain a healthy diet, exercise, get plenty of sleep and see your own doctor as needed.
4. Maintain your religious beliefs and spiritual values.
5. Take breaks each day.
6. Learn how to communicate effectively with doctors.
7. Be open to new technologies that can help you care for your loved one.
8. Organize medical information so it’s up to date and easy to find.
9. Make sure legal documents are in order.
10. Finally, give yourself credit for doing the best you can in one of the toughest jobs there is!

(Source: Caregiveraction.org)
Reducing Your Risk

While some risk factors such as genetics or age cannot be changed, other lifestyle changes, including healthy eating habits, regular exercise and smoking cessation, can minimize risks. Taking prescription medications to reduce cholesterol levels and blood pressure is also important.

• Keep mentally active. Read, do puzzles or learn a new skill.
• Keep physically active.
• Maintain a heart-healthy diet like the Dietary Approaches to Stop Hypertension (DASH) or the Mediterranean diet.
• Get enough sleep. Seek treatment for insomnia and sleep apnea.
• Develop new hobbies.
• Avoid excessive alcohol use.
• Quit smoking.
• Have an active social life.
• Practice good stress management.
• Manage your blood pressure.
• Protect your head—wear a seatbelt in the car and a helmet when participating in sports.
• Seek treatment if you have depression, anxiety or other mental health condition.

Impact on Family Caregivers

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>59%</td>
<td>rated the emotional stress of caregiving as high or very high</td>
</tr>
<tr>
<td>52%</td>
<td>had great deal of stress about family relationships</td>
</tr>
<tr>
<td>47%</td>
<td>had great deal of stress about financial issues</td>
</tr>
<tr>
<td>39%</td>
<td>experienced depression (compared with 17% for non-caregivers)</td>
</tr>
<tr>
<td>38%</td>
<td>rated physical stress of caregiving as high or very high</td>
</tr>
</tbody>
</table>

(Source: Alzheimer’s Association)
Many persons with dementia, especially those raised in religious households, benefit from attending services and having home visits. Connecting with their faith and faith community may bring peace, hope and some sense of familiarity. They can often take part in age-old rituals and celebrations and enjoy hearing favorite music and readings.

Some aspects of faith that may bring comfort are:

**Music** can soothe the soul and connect someone to faith and memory despite the level of cognitive loss. Recent studies show that listening to music and singing can boost brain activity and recall in dementia patients. Even a person not able to converse with caregivers may quietly sing the right words to an often-repeated and much-loved spiritual song or hymn.

Listening to or reciting **prayers**, especially those often-repeated or memorized in earlier years, can connect an individual to faith, memories and a sense of the familiar. Incorporate a treasured prayer book or favorite rosary beads; the use of both visual and touch help to cue memory.

**Readings** also provide prompts to reconnect to the faith memory. Reading is a skill a person with a progressive dementia like Alzheimer’s Disease maintains for a long time. Prepare large print cards with a loved one’s favorite passages to read together.

Daily and cyclical **rites and celebrations** related to one’s faith can involve the senses of taste, touch and smell that are often not affected by dementia. They, along with the familiar ritual, allow all to use those still-active senses and participate in the person’s faith tradition.

**Supporting Family Caregivers**
Providing care for a loved one with dementia can take a heavy toll on a family caregiver. Because care can last for years, the caregiver can feel weary, isolated, frustrated, depressed and grieving the loss of who the person once was. Faith communities can encourage the caregiver to practice good self-care and provide support through gifts of service and direct resources.

**Dementia-Friendly Faith Communities**
Adjusting your faith community’s expectations and approach to people with dementia and their caregivers enable them to feel loved, valued and that they belong to the community. Creating shorter special services, providing a quiet room, ensuring your facility is safe and accessible, educating members, finding ways to include the person with dementia and treating them with respect are just some ways you can explore becoming dementia-friendly. You can find more ideas on the Internet.
Alzheimer’s Patient’s Prayer

by Carolyn Haynali

Pray for me I was once like you.

Be kind and loving to me; that’s how I would have treated you.

Remember I was once someone’s parent or spouse. I had a life and a dream for the future.

Speak to me. I can hear you even if I don’t understand what you are saying. Speak to me of things in my past of which I can still relate.

Be considerate of me; my days are such a struggle.

Think of my feelings because I still have them and can feel pain.

Treat me with respect because I would have treated you that way.

Think of how I was before I got Alzheimer’s; I was full of life, I had a life, laughed and loved you.

Think of how I am now. My disease distorts my thinking, my feelings and my ability to respond, but I still love you even if I can’t tell you.

Think about my future because I used to. Remember I was full of hope for the future just like you are now.

Think how it would be to have things locked in your mind and can’t let them out. I need you to understand and not blame me, but Alzheimer’s.

I still need the compassion and the touching and most of all I still need you to love me.

Keep me in your prayers because I am between life and death.

The love you give will be a blessing from God and both of us will live forever.

How you live and what you do today will always be remembered in the heart of the Alzheimer’s patient.