DEMENTIA: A SURVIVAL GUIDE FOR FAMILY CAREGIVERS

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DEMENTIA: CAUSES AND TREATMENTS

WHAT IS DEMENTIA?

Dementia is not a specific disease. It is a term that describes a decline in cognitive abilities severe enough to impair normal everyday activities. While memory loss is a common symptom of dementia, by itself it does not mean that a person has dementia. Doctors diagnose dementia only if two or more brain functions - such as memory, orientation, the ability to learn, language skills, reasoning or judgment - are significantly impaired and the cognitive deficits interfere with one's ability to independently perform everyday activities like driving, paying bills, housekeeping or preparing meals. In the latter stages of dementia, personal care skills like bathing and dressing can be impaired. A person with dementia also may exhibit personality changes, **loss** of emotional control and behavioral problems such as agitation, paranoia and hallucinations.

Dementia is most common in older adults, but is not a normal part of aging. It is caused by a number of medical conditions which trigger abnormal brain changes that lead to a decline in thinking skills. These changes can start in the brain decades before observable symptoms appear. Consequently, the symptoms of dementia can start slowly and gradually worsen over time.

In some cases, dementia can be reversed or stopped from getting worse. In others, it is a permanent process and treatment efforts are geared toward slowing the progression. As with any other medical condition, it is essential that a proper evaluation be made when the symptoms of dementia first appear, so that appropriate treatments can be offered.

WHAT ARE COMMON FORMS OF DEMENTIA?

ALZHEIMER'S DISEASE is the most common form of dementia in older persons. It is marked by the slow destruction of nerve connections in the brain. The clinical course of Alzheimer's dementia is usually characterized by a gradual onset and progressive decline in cognitive and functional abilities. Currently, Alzheimer's is neither curable nor reversible, however it is being aggressively studied worldwide by medical researchers. Current treatments focus on medications to treat the symptoms and to attempt to slow the rate of progression. (See pages 5-6)

VASCULAR DEMENTIA is caused either by a severe narrowing or blockage of arteries that carry blood to the brain, or from strokes caused by an interruption of blood flow to the brain. The first symptoms of vascular dementia usually start suddenly, and progression is often marked by abrupt "step downs" of cognitive abilities. But vascular dementia may also slowly and progressively worsen over time. Currently, vascular dementia is neither curable nor reversible. Treatment involves preventing additional strokes by addressing underlying risk factors and diseases, such as high blood pressure and high cholesterol, and by use of blood-thinning medications.

PARKINSONIAN SPECTRUM DISORDERS. Persons with late-stage Parkinson's Disease or "Parkinson's Plus" Diseases (such as Progressive Supranuclear Palsy) may develop a dementia. This spectrum of disorders is often characterized by abnormal motor symptoms, such as tremor, instability, stiffness and slowness of movement. Cognitive deficits can range from relatively isolated impairments to global impairments. Currently, these disorders are neither curable nor reversible. Treatments are meant to address the individual's physical, emotional and behavioral symptoms.

LEWY BODY DEMENTIA is marked by small protein deposits called "Lewy bodies" found in deteriorating nerve cells in the brain. Lewy Body Dementia is characterized by cognitive decline with pronounced fluctuation in alertness and attention, visual hallucinations and abnormal motor symptoms, such as tremor and rigidity. Currently, Lewy Body Dementia is neither curable nor reversible. Treatments are meant to address the individual's physical, emotional and behavioral symptoms.

FRONTOTEMPORAL DEMENTIA (FTD) is caused by a deterioration of brain cells in the frontal and temporal lobes of the brain. Initial symptoms include behavioral and personality changes (e.g., poor judgment and impulsiveness) or language changes (e.g., word finding and comprehension deficits). In most cases, memory is generally preserved in the early course of these diseases. Currently, FTD is neither curable nor reversible. Treatments are meant to address the individual's physical, emotional and behavioral symptoms. Persons presenting with language changes may benefit from speech-language treatment early in the course of the disease

WHAT OTHER CONDITIONS CAN CAUSE DEMENTIA OR CHANGES IN COGNITIVE ABILITIES?

Doctors have identified other conditions that can cause dementia or dementia-like symptoms. In the following conditions, cognitive problems may sometimes be reversed with appropriate treatment. These include but are not limited to:

TRAUMATIC BRAIN INJURY: Traumatic brain injury (TBI) is a change in the normal function of the brain due to a head injury commonly caused by events such as a fall or motor vehicle crash. Persons who sustain a TBI often experience a varying combination of physical, cognitive, or emotional symptoms, with the consequences of the injury typically depending upon the severity and location of the injury. In general, persons who sustain mild injuries are typically expected to make a speedy recovery (usually over the first three months) and generally return to near normal levels of prior functioning. Moderate-to-severe brain injuries can result in more permanent cognitive, physical, and emotional challenges and recovery typically occurs over a longer period of time, with the most progress being made in the first six to nine months. After this, functional recovery typically begins to plateau but slow improvement following this period is not uncommon. Treatment varies depending on the severity and can include medication to treat symptoms of TBI (e.g., mood and neurobehavioral functions), and rehabilitation therapies (e.g., physical therapy, occupational therapy, speech therapy, cognitive therapy) to assist in the recovery of function and skills. Strategies for treating cognitive and functional symptoms that persist past the acute post-injury period are often the same as those for treating Alzheimer's or another specific type of dementia.

HYPOXIA: Hypoxia occurs when there has been a significant disruption in the flow of oxygen to the brain. This can cause serious impairments of physical, cognitive, and psychological skills. The rate and extent of recovery are unpredictable and largely depend on which parts of the brain have been affected, and how severe the injury is.

BRAIN TUMOR: A tumor can cause damage by increasing pressure in the brain, by pressing the brain against the skull, and/or by invading and damaging healthy brain tissue and nerves. Medical or surgical treatment of the tumor can sometimes reverse or improve the resulting symptoms cognitive decline or personality change; however, depending upon the degree of brain injury sustained because of pressure on brain cells and structures, a person may be left with some degree of permanent cognitive dysfunction or other neurological deficits.

SUBDURAL HEMATOMA is a collection of blood (a hematoma) that forms on the surface of the brain. It often results from head injury but can occur spontaneously in older persons, especially those who take blood thinning medications. Symptoms may include numbness and weakness, slurred speech, drowsiness and mental confusion. Cognitive changes occur and progress quickly or slowly depending upon the size and location of the hematoma. This condition requires emergency treatment that may include medications and/or surgery to drill a small hole in the skull to allow the blood to drain and relieve pressure on the brain. Depending upon the degree of brain injury caused by pressure from the hematoma, a person may be left with some degree of permanent cognitive disability.

NORMAL PRESSURE HYDROCEPHALUS (NPH) is a condition that arises when the flow of spinal fluid in and out of the brain is obstructed, causing it to backup into areas of the brain and creating increased pressure that can affect brain tissue. NPH often results from a prior brain injury or infection, and commonly produces symptoms of walking difficulties, loss of bladder control and cognitive changes. NPH may often be corrected with surgery to install a small tube (a "shunt") into the brain to drain off the excess fluid. The degree of cognitive improvement after such treatment, however, varies among patients.

ALCOHOL USE: Alcohol use can contribute to variation in cognitive functioning, depending on the pattern and severity of use. Chronic and severe alcohol use can lead to nutritional and vitamin deficiencies and interfere with the formation of new brain cells. Long-term and/or heavy use of alcohol increases the risk of alcohol-induced cognitive impairments and this risk is further increased in older adults. Abstinence from alcohol may result improvements, and the longer the period of abstinence the greater the cognitive improvements are regardless of lifetime use patterns. This pattern of cognitive recovery is slower in older adults.

INFECTIONS of the brain and central nervous system, from disorders such as meningitis, encephalitis Lyme Disease or late-stage syphilis, will cause inflammation that damages brain cells if not properly treated

HORMONE DISORDERS involve body glands that secrete and/or regulate hormones. These include the thyroid, parathyroid, pituitary and adrenal glands. Severe and/or prolonged imbalances in such hormones can lead to dementia if not corrected.

METABOLIC DISORDERS such as kidney, liver and pancreas diseases, can cause symptoms of dementia, and may be progressive and irreversible if left untreated.

WHAT CONDITIONS ARE NOT DEMENTIA?

DEPRESSION can make an older person appear to be demented because it can cause inattention, apathy and impair one's ability to learn and remember new things. Persons with a significant depression, but without any underlying dementia, should regain cognitive skills if their mood is successfully treated. However, depression can also be a symptom of dementia. In such cases, treating depression is still important but does not fully restore cognition. Treatment options include medications and counseling.

DELIRIUM is an abrupt onset of confusion and rapidly fluctuating mental states. The person may also be disoriented, drowsy or incoherent, and may have personality changes. A critical step in the treatment of delirium is discovering and treating the underlying contributing factor(s), as delirium is usually caused by a treatable physical illness. Persons with delirium may make a complete recovery after the underlying illness is treated.

MEDICATION EFFECTS Many medications may impact memory and cognitive function when used alone or in combination with other drugs. Specifically, some medications used to treat seizures, pain, sleep problems, allergies or colds, and depression and anxiety can interfere with attention, memory, and other cognitive faculties. As aging occurs, brains can become more sensitive to the effects of medication and avoiding medications that can affect cognition can help to optimize brain function. When such medications are stopped or decreased, the cognitive symptoms usually lessen or stop.

AGE-RELATED COGNITIVE DECLINE Subtle changes in thinking speed, attention, and memory occur naturally as part of the aging process. These can result in occasionally "senior moments" such as occasionally forgetting why you walked into a room, accidently mixing up the names of family members, or occasionally struggling to find the right words to say. The fact is these events also happen during younger years but likely went unnoticed with little worry. With age-related cognitive decline you may occasionally experience these "brain blips" but you are still able to complete your daily activities (e.g., driving, managing your finances, taking your medications, or cooking) by yourself and without concerns.

MILD COGNITIVE IMPAIRMENT (MCI) is a condition in which a person experiences memory and thinking difficulties more frequently than others their own age and is not a normal part of aging. Despite these cognitive changes, the person is still able to complete their daily activities by themself; however, it may take greater effort or strategy than usual to complete these tasks. Since the cognitive concerns do not affect functional independence, the declines are not diagnosed as dementia, however many persons with MCI are at higher risk of eventually developing a dementia.

MEDICATIONS TO TREAT DEMENTIA

Approximately three-fourths of all cases of dementia are caused by Alzheimer's Disease or vascular brain disease, or by a combination of both disorders. Medications are available that may help to stabilize mental function in persons with Alzheimer's disease, vascular dementia, and with mixed Alzheimer's and vascular dementia. None of these medications stop the progression of cognitive decline, but they may improve mental function for a period of time. This can help ease the burden of family caregivers and delay placement in a long-term care facility.

WHAT MEDICATIONS ARE CURRENTLY BEING PRESCRIBED?

There are two classes of medications currently being prescribed to treat Alzheimer's dementia: "cholinesterase inhibitors" such as **donepezil** (the generic form of Aricept), **rivastigmine** (the generic form of Exelon), **galantamine** (the generic form of razadyne), and an "NMDA receptor antagonist", **memantine** (the generic form of Namenda). **Namzaric** (a brand-name combination of memantine and donepezil) can also be prescribed.

The generic forms of these medications are as effective as their brand-name counterparts and usually less expensive.

HOW DO THESE MEDICATIONS WORK?

Cholinesterase Inhibitors: Acetylcholine is a substance manufactured by nerve cells in the brain. It helps transmit "messages" between cells, allowing a person to think and perform tasks. Both Alzheimer's disease and vascular brain disease destroy some of the brain cells that make acetylcholine. Medications that inhibit cholinesterase temporarily boost the levels of acetylcholine in the

brain, may help improve memory and cognitive function. In some cases, the benefit is limited to keeping mental function stable for a period of time.

NMDA Receptor Antagonists: This medication regulates the activity of glutamate, another "messenger" chemical in the brain. Glutamate triggers NMDA receptors in the brain to allow a controlled amount of calcium to flow into nerve cells to help the brain process, store and retrieve information. Excess amounts of glutamate cause NMDA receptors to allow too much calcium into nerve cells, leading to disruption and death of cells. Memantine (Namenda) may protect cells against excess glutamate by partially blocking the NMDA receptors.

WHAT CAN I EXPECT THESE MEDICATIONS TO DO FOR MY LOVED ONE?

Cholinesterase Inhibitors: Between 30%-50% of those taking cholinesterase inhibitors experience a mild but noticeable improvement in attention, concentration and in the ability to perform daily activities. The average improvement was comparable to "rolling back" the disease symptoms anywhere from 6-12 months. Cholinesterase Inhibitors appear to be effective in all stages of dementia.

NMDA Receptor Antagonists: Memantine has proven to be modestly effective in improving functional performance in persons with moderate to late-stage dementia. Studies failed to show an advantage to using memantine in mild dementia.

WHAT SHOULD BE CONSIDERED WHEN USING THESE MEDICATIONS?

Dementia medications differ in the number of daily doses required and the types of potential side effects. Some are taken once daily and others are taken twice daily. All come in tablet or capsule form, and **rivastigmine (Exelon)** also comes in a once-daily transdermal patch.

The most common side effects of all **cholinesterase inhibitors** are nausea, vomiting, loss of appetite and diarrhea. The most common side effects of **memantine (Namenda)** are dizziness, headache and constipation. When they occur, these symptoms tend to be mild and get better with time. Side effects may be avoided by starting with the smallest possible dose of medication, then gradually increasing it to the higher dose. When side effects do appear, they may be able to be overcome by reducing the dose for a week or so, and then increasing it again. These medications may not be appropriate for persons with certain medical conditions. A physician can determine whether a person has any medical conditions or potential risk factors that would prevent them using these medications.

As a rule of thumb, if a person is taking one of these medications - and is doing well - they should not switch to another. If they are not doing well on a particular medication (ie. having side effects, or showing increased symptoms after 6 months of use), it would be reasonable to stop that drug and start another, either in the same or a different class. If a person cannot take, or does not benefit from, any of these currently prescribed medications, it would be reasonable to enroll them in a clinical research trial for medications that are still being tested.

WHAT DO THESE MEDICATIONS COST?

In 2021, a 30-day supply of donepezil retails for up to \$240. Rivastigmine retails for up to \$170, and rivastigmine patches retail for up to \$480 for a 30-day supply. A 30-day supply of galantamine retails for up to \$165. Memantine retails for up to \$390, and Namzaric (memantine/donepezil) retails for up to

\$525 for a 30-day supply. These are the prices you might expect to pay if you are paying "cash" without insurance. These medications are covered by many of the Medicare-approved prescription drug plans, and the website: https://www.goodrx.com allows you to compare prices between pharmacies, and print coupons that can provide substantial cost savings.

Additionally, the pharmaceutical companies that make these medications may offer them free of charge or at a discount to persons of limited means, and without prescription drug coverage. Speak to your physician or pharmacist about these Patient Assistance Programs, or go online to Benefits Checkup: www.benefitscheckup.org

HOW DO I OBTAIN A PRESCRIPTION FOR THESE MEDICATIONS?

Any medical doctor may prescribe them. However, it is essential that an accurate diagnosis be made first. To do this, the physician must perform a thorough physical examination, blood tests, and a brain scan. The physician should also administer basic cognitive tests and should review all the medications the person is taking to look for those that could contribute to the problem. It is vital that the physician gather a detailed history from family members or caregivers about the type of symptoms, onset of these symptoms, and progression of the cognitive and functional decline. A thorough evaluation will help the physician identify and treat other medical conditions that may be mistaken for Alzheimer's or vascular dementia.

ARE NEWER MEDICATIONS CURRENTLY BEING TESTED?

Clinical research studies are part of a careful, scientific process to see whether new treatment approaches are safe and effective. After first being tested in the laboratory, and then with animals, treatments that appear promising are then tested on humans in carefully designed clinical trials.

Interested persons are first screened to see if they are candidates to participate in a clinical trial. Those selected for a trial will be divided into two groups: one group will receive the trial medication and another will receive a "placebo", a pill or patch with no active medication. Study participants agree to a series of follow-up appointments and phone calls to track their progress and the effects of the study treatment over time. The cost of study medications, physical and cognitive examinations and lab tests are covered by the research sponsor.

For information about clinical trials in the Omaha area, contact the UNMC Neurology AD Trials staff at (402) 552-6241.

The Alzheimer's Association sponsors a program called "TrialMatch" which can match people to clinical trials around the country. To access this service, call (800) 272-3900 or go online to

Clinical Trials for Alzheimer's & Dementia | Alzheimer's Association

TIPS FOR CARING FOR A MEMORY-IMPAIRED PERSON

MEMORY AIDS (clocks, calendars and written notes) help a person stay oriented.

Much of what you say to the person may soon be forgotten. Be prepared to **REPEAT** yourself sometimes often.

Speak in a **CALM VOICE**. Make brief, simple statements. Try using touch and **DIRECT EYE CONTACT** when responding to emphasize what you say.

Avoid presenting the person with more than one thought at a time, and **LIMIT CHOICES** ("Either/or", rather than "multiple choice").

DISTRACT the person from an irritating or repetitive topic by using a word from the conversation to **RE-DIRECT** them or change the subject. Try such pleasurable distractions as taking a walk or drive, looking at family photos, playing music or giving the person a simple, repetitive task to perform, such as folding towels.

If distractions fail, try to **IGNORE** repeated questions. This may initially anger or agitate the person, but the questions may stop if they are not reinforced by your behavior. Ignoring is an especially good tactic when you are irritated. It may prevent the person from picking up on your irritation.

Most memory-impaired persons function best when following a **FAMILIAR ROUTINE** in **FAMILIAR SURROUNDINGS**. Avoid abrupt or frequent changes of routine, activities and location. Avoid discussing plans for non-routine activities/appointments with the person until just prior to the event to avoid agitation and repeated questions days in advance.

PRAISE and POSITIVE REINFORCEMENT helps a person maintain dignity and self-care skills. When correcting or directing them, avoid negative commands ("Don't do that"). Use a positive focus ("Let's do this").

If the person's cognitive skills continue to worsen, closely monitor their ability to perform tasks and be prepared to **LOWER YOUR EXPECTATIONS** for their performance. Allow the person to do as much for themselves as they possibly can, even if they are slower and less efficient. Take over a task completely only when they cannot perform it even with step-by-step instructions or help. Complex or risky tasks (such as driving, using appliances or managing financial affairs) may have to be assumed by others sooner.

To include the person in social conversations, refer to positive memories of the past. **ENCOURAGE REMINISCENCE**, as the person is able to remember past events better than present.

Suggest a word or name the person is searching for in conversation, but **AVOID CORRECTING MISTAKES** already made. Contradicting or arguing with the person may only cause upset and humiliation.

ANTICIPATE and avoid activities and discussions that will provoke anger or agitation. Prevention is the most effective approach to reduce behavior problems.

LOOK FOR A REASON BEHIND TROUBLESOME BEHAVIOR. Is the person frightened, in pain, hungry or needing to toilet? Respond to the need or emotion you feel the person is trying to express.

If the person becomes extremely agitated or aggressive, **REMOVE THEM FROM THE STRESSFUL SITUATION** or place. Avoid quick gestures and try to calm the person with a soothing and reassuring voice and gentle touch. Do not try to reason with the person, as their ability to understand logic and reason is impaired. If you feel threatened, remove sharp or dangerous objects from the area and stay out of reach. Leave and seek help if needed.

Make note of when a catastrophic reaction occurs. Is there a pattern (ie. time of day, type of activity, interaction with a specific person) that can be identified? **SIMPLIFY THE ENVIRONMENT** by reducing extra people, clutter, noise and activity. Soft music, or holding a doll or a stuffed animal may ease agitation and calm fears in a severely impaired person.

While use of medication to control behavior should be a last resort, **MEDICATIONS MAY BE NECESSARY** to control depression, hallucinations, paranoia, sleeplessness and extreme agitation. Discuss this with your doctor.

Honestly **AKNOWLEGE TO THE PERSON THAT THEY HAVE A MEMORY PROBLEM**, but confronting them with their loss of ability may lessen their sense of dignity and self esteem. Try to remind the person how much they can still do for themselves. Reassure them that they are still loved and valued. Try to discuss openly the person's memory and behavior problems with family, friends, neighbors and others who will have regular contact with him/her. People tend to respond more appropriately and offer assistance when they understand the situation.

Emotional support and **RESPITE** from care giving responsibilities are essential to helping you cope. Arrange for someone else to assume your care giving duties for several hours at a time on a regular basis so you can get out and "recharge your batteries". You cannot provide good care for your loved one if you neglect your own needs.

Consider joining a self-help or **SUPPORT GROUP**. These offer an excellent setting in which to express your feelings and learn creative approaches to solve the challenges you face in providing care. Your local Area Agency on Aging or regional chapter of the Alzheimer's Disease Association can direct you to such groups.

BE PATIENT WITH YOURSELF. Recognize that you will make mistakes and will become angry and impatient at times. Know your own limits and try not to feel guilty when you have to say "no" to others. Remember, you are only human!

HELPFUL RESOURCES FOR CAREGIVERS

CAREGIVER CALENDARS

Downloadable apps and on-line, interactive "Help Calendars" enable family members to schedule and coordinate tasks such as meals, medication refills, rides to medical appointments, and visits. A primary caregiver can post tasks that require help so volunteers can easily see what's needed. Regular reminders are sent to volunteers so that no one forgets their commitments.

Care Team Calendar | Alzheimer's Association

CareCalendar.org | The official site of helping families in need

Care Calendar Website | Lotsa Helping Hands

Personal Health Journals for Any Condition | CaringBridge

Caring Village | FREE help for families and caregivers

RECOMMENDED READINGS:

Books, brochures and videos recommended by the Alzheimer's Association for family members, professional caregivers, and for those experiencing dementia are available through your local Alzheimer's Association chapter, at public libraries and book stores. Items not in stock can be special-ordered.

Internet book sellers such as www.amazon.com and www.barnesandnoble.com will send items to you, or direct you to out-of-print book providers. Their web sites offer detailed descriptions of the focus and content of most books. They also sell downloadable e-book versions.

RECOMMENDED VIDEOS:

Dementia in Long Term Care

This website created by an Omaha geriatrician and geriatric psychiatrist offers short videos, power point presentations and care tips for professional and family caregivers.

<u>Dementia in LTC | Internal Medicine | University of Nebraska Medical Center (unmc.edu)</u>

UCLA Alzheimer's and Dementia Care Video Series: Seven videos highlighting problematic behaviors, and strategies for caregivers to assess and respond to them.

Caregiver Education | UCLA Alzheimer's and Dementia Care Program - Santa Moncia, CA (uclahealth.org)

INTERNET WEBSITES

Alzheimer's Disease Association

https://www.alz.org

Alzheimer's Foundation of America

https://alzfdn.org

Caregiver Action Network https://caregiveraction.org

Dementia Society of America https://www.dementiasociety.org

Family Caregiver Alliance https://www.caregiver.org

Frontal-Temporal Dementia https://www.theaftd.org

Hydrocephalus Association https://www.hydroassoc.org

Lewy Body Dementia https://www.lbda.org

Medline Plus https://medlineplus.gov/alzheimerscaregivers.html

National Alliance for Caregiving https://www.caregiving.org

National Institute on Aging https://www.nia.nih.gov/alzheimers/topics/caregiving#pubs

ALZHEIMER'S DISEASE & RELATED DISORDERS ASSOCIATION

National Alzheimer's Association

https://www.alz.org

225 N. Michigan Ave. Floor #17 Chicago, IL 60601 (800) 272-3900 (24 Hour Help Line)

Local Chapters/Satellite Offices: All are reachable toll-free at (800) 272-3900

Nebraska Chapter

11711 Arbor St., Suite 110 Omaha, NE 68144 (800) 272-3900 Nebraska Chapter (alz.org)

lowa Chapter

1730 28th St. West Des Moines, IA 50266 (515) 440-2722 Greater Iowa Chapter (alz.org)

Satellite Offices

Burlington: (319) 237-4900 Cedar Rapids: (319) 294-9699 Council Bluffs: (712) 308-8946 Davenport: (563) 293-8058 Dubuque: (319) 238-7783 Fort Dodge: (515) 212-3226 Sioux City: (712)454-5034 Waterloo: (319) 277-4100

Heart of America Chapter (Northwest Missouri & Northeast Kansas)

3846 W. 75th St. Prairie Village, KS 66208

(913) 831-3888

Heart of America Chapter (alz.org)

Satellite Offices

St. Joseph, MO: 927 Faraon St. (64501)

(816) 364-4467

Topeka, KS: 3625 SW 29th St., Suite 102 (66614)

(785) 271-1804

South Dakota Chapter

(800) 272-3900 (24 Hour Help Line) South Dakota Chapter (alz.org)

You may download and print a copy of this and other patient education documents from the resources link on our Internet web site: https://www.nebraskamed.com/geriatrics/resources

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