

# Orr Memory Clinic Patient Educational Material

## Dementia

### **So you or a loved one has been diagnosed with “dementia.” What exactly does that mean?**

“Dementia” is a loss of brain “power,” not due simply to normal aging, to the point where it significantly impacts your ability to function for your age. Brain “power” refers to memory, language, ability to use tools or navigate in your environment, and multistep or complex decision making, including how to behave appropriately in social situations.

Dementia is a behavioral diagnosis. It is not diagnosed simply from a brain scan or laboratory studies. It requires understanding a patient’s style of decision making and to some extent personality and whether or not there are acquired changes that are not better explained by other causes, such as a mood or anxiety disorder, sleep disorder, or the effects of a medical problem or even medications. Therefore, a “workup” of suspected dementia will include a structural scan of the brain (CAT scan or MRI), laboratory studies, and an in -person examination that may look at some parts of motor or neurological function. Additionally, memory or neuropsychological testing (about 2-1/2 hours of paper and pencil testing with a specialized neuropsychologist) is also an important piece of the workup. Occupational therapy testing can be useful in looking at the ability to do things in your environment safely, such as cooking, managing money safely, or even driving. The goal for most people with dementia is to make sure that should they decide to stay living in their own home that they can continue to do so safely.

### **What is the relationship of “dementia” to Alzheimer’s disease?**

Alzheimer’s is a specific disease that causes dementia. It is caused by several microscopic proteins that slowly and subtly begin to appear in the brain and gradually cause loss of brain neurons. We still do not know exactly what causes Alzheimer’s disease, but the #1 risk factor is still simply aging. While it does tend to run in families it is possible to get the disease even if you are the only one in the family that has the diagnosis. Other risk factors include a history of head trauma, certain medical conditions including diabetes, and even untreated depression. There are many other diseases (e.g. Lewy body disease, frontal lobe dementia, or Parkinson’s disease) that can also cause dementia. The goal of the dementia workup is not only to find out if a person has dementia, but possibly determine the specific cause. Oftentimes, in the early stage of dementia, it is not possible to accurately determine the cause. In most cases, a definitive cause of dementia can only be determined on autopsy. This includes the diagnosis of Alzheimer’s disease.

When a person first starts to develop symptoms of dementia the symptoms are extremely mild and often overlap with changes due to normal aging. Thus, dementia is often not recognized

until several years into the disease process. By the time Alzheimer's dementia is diagnosed, most people are well in to mild stage but are often even in the moderate stage. By the moderate stage a person will have good days and bad days. On bad days, they may become lost particularly in an unfamiliar area, forget entire conversations, or lose important items or forget important appointments. At this stage, they are vulnerable to making mistakes with their medications, not following a diabetes regimen/diet, or intermittently showing instances of impulsivity or poor judgment placing their safety at risk. They will start to require more assistance and supervision. Gradually, they will shift from only a few bad days per month, to a few bad days per week, to eventually more bad days than good in terms of seeing more confusion and forgetfulness.

### **What if I am only suspected of having dementia or Alzheimer's disease or worried I might get it and I wish to reduce my risks?**

Though we do not know the precise cause of Alzheimer's or other causes of dementia, current thinking is that there are "inflammatory" processes the cause a cascade of changes in the brain leading to the abnormalities. Currently, there are a number of healthy lifestyle choices that one can make with increasing evidence that they can significantly decrease one's risk. Recently, it is suggested that one think of the acronym **S.H.I.E.L.D.**

**Sleep:** It is believed that many of the abnormal proteins or metabolic products that need to be cleared from the brain happen much better during times of sleep. It is recommended that everyone attempts to get a good 8 hours of sleep. Even naps can be helpful.

**Handle Stress:** Chronic stress is well known to be deleterious to a person's physical and mental health. The stress hormone, cortisol, is elevated during times of stress and is also known to cause loss of certain brain neurons. Conditions such as depression and anxiety, when not treated, contribute to a person's stress level as well. Learning to maintain a sense of calm under times of stress has clearly been shown to be helpful. Activities such as meditation or tai chi, as well as other exercises, can be enormously beneficial.

**Interact:** It is believed that social interactions help continue to stimulate the brain which helps to maintain its overall health. Social interactions provide an important sense of well-being and even purpose as well.

**Exercise:** You need to check with your primary care provider or other specialists to determine an exercise program right for you, however, engaging in mild to moderate vigorous exercise is extremely important in maintaining both physical and mental health. Recently it has been recommended that to help with healthy aging one should engage in 20 minutes of vigorous exercise each day on average.

**Learn:** The old saying of "use it or lose it" is true of both physical and mental abilities. Continuing to engage in learning new information or activities stimulates brain activity and connections. One should be careful not to overdo this which can lead to anxiety and frustration or even stress. It has been shown that mental activities that involved processing and 3-

dimensional space likely engages more connectivity of the brain than simply reading or looking at a computer screen. Therefore, attempting to incorporate even mild physical activity with the learning process likely would be the most beneficial (e.g. bird watching, beanbag toss, doing puzzles or cards).

**Diet:** We believe that as the brain ages its ability to handle sugars may become impaired. This is perhaps why diabetes is also thought to be a risk factor of having dementia. Most experts will now recommend the Mediterranean diet, or any other similar diet that relies more on beans or legumes for nonfatty proteins, rather than red/fatty meats; Olive oil or certain vegetable oils should be added with an emphasis on omega-3 fatty acids, which have been shown to be beneficial for a number of conditions including certain dementias and even depression. Alcohol should only be consumed in moderation, particularly if you are on certain medications. Some patients need to avoid alcohol altogether.

### **If I am diagnosed with dementia or Alzheimer's disease are there any treatments?**

Yes, there are medications to help slow the progression of symptoms. However, there are no medications as yet approved that actually cure the disease itself. We believe these medications are more helpful in the earlier stage of the disease. Nevertheless, as the disease progresses the medications can help with memory, decision making, and even the frequent neuropsychiatric symptoms of depression, anxiety, and paranoia. Most patients tolerate these medications relatively well. They rarely, if ever, cause people to be tired or lethargic. There are rare instances of the medications causing anxiety or agitation. The main side effects are to cause mild, temporary upset stomach or diarrhea and associated decreased appetite with weight loss. This usually resolves in the first week or two. There can be ongoing problems with disturbance of sleep and vivid dreams, though rarely nightmares, which is why we usually prescribe the medications in the morning if they are taken only once per day.

It is not unusual for persons to develop anxiety in the very early stages, particularly if the memory impairment is not recognized. Under enough stress, this can turn into sadness and depression. It is estimated that 60-80% of patients will also develop paranoia or even psychotic symptoms. The most common delusions are to accuse a spouse of cheating on them, somebody stealing from them, or even believing that a spouse or caregiver has been substituted with a stranger who looks like them. Some patients even fail to recognize their own face when looking in the mirror and believe a stranger is looking at them through window. This can create significant distress and agitation. There are a number of psychiatric medications that can reduce or control these neuropsychiatric symptoms, though some are quite powerful and have many side effects that require very close monitoring.

### **Besides medications what else can I do?**

It is extremely important for patients but particularly families and caregivers to educate themselves about this disease process. There are many resources available, particularly from the Alzheimer's Association. We would strongly recommend that you would start by looking at the website: [www.alz.org](http://www.alz.org). There are many resources, particularly for caregivers, and many descriptions about what to expect and how to handle a variety of situations. There is even

information about vitamin supplements and research drug trials that one can consider participating in. In particular, there are many resources for caregivers including caregiver support and training.

Environment is extremely important for persons with dementia. Change can be difficult to cope with and can even promote anxiety and agitation, if not paranoia. Therefore, consistency in routine can be very helpful and even calming. Maintaining structure, including regular times for activities, sleep, and even meals can all be helpful. Thus, a change in routine or location by traveling can cause anxiety, confusion, paranoia, or even hallucinations – at times the reaction can be severe. Being aware of this potential reaction, caregivers can take steps to avoid this from happening or making sure they have appropriate support to handle any such reaction.

### **Two rules for caregivers:**

1. The patient will only do as well as you are doing. This means that you must take care of yourself. You must make sure that you are getting enough rest or sleep and you are able to take breaks from a job that can turn into 24 hours a day. Make certain to make healthy choices about your lifestyle.
2. You cannot do it alone. You cannot stay on duty 24 hours a day 7 days a week for very long. You must recruit other family members, friends, and other sources of support to help you out. Once again, the Alzheimer's Association can provide suggestions and the clinic can help provide you with some resources.

### **Other considerations for a diagnosis of dementia:**

1. Safety and driving: Any potentially hazardous activity must be closely monitored. This includes driving. The only way to actually know if somebody is safe to drive is to have a behind the wheel driving evaluation. This can be done a number of places, such as the courage Center which charges approximately \$300. You can always contact your local DMV as well. They may find that you can drive safely with certain restrictions. Any weapons such as guns should be locked away so that the patient does not have independent access to them. Similarly, all use of power tools should be closely monitored. Other activities that could be potentially hazardous, such as cooking, getting up on ladders, or generally anything that requires the cognitive ability to assess risks should be assumed to be impaired and requires monitoring.
2. Ultimately, all medications should be monitored. Additionally, it may be necessary to monitor the patient's diet. Forgetfulness may cause them to make poor choices and place their health at risk without realizing it. In some types of dementia, the patient will crave sweets or even lose the ability to discriminate hunger from satiety. They begin to "graze" on caloric snacks leading to weight gain. When dementia is advanced it is not unusual for the patient to only eat when food is placed in front of them, otherwise they may literally forget to eat. They also could become dehydrated and progressively weaker.

3. Legal and financial considerations: It is important for everyone to have a health care directive that tells others what medical decisions you would like made for you in the event you are unable to speak for yourself. Often a DURABLE POWER OF ATTORNEY can be set up for both medical and financial decision making. It is recommended that you consult with an attorney to make sure that these legal tools are put in place as soon as possible. Only under rare circumstances do things like guardianship or conservatorship need to be pursued.
4. Living situation: Most people want to continue to live in their own home with their spouse or significant other throughout the course of their disease. Increasingly, this is being accomplished by very careful planning and making good use of resources. The clinic can provide you with resources for things such as companion care, or even help with upkeep in the home. Senior Linkage is an important resource. Another important resource is daycare programs that the patient attends usually from about 9 in the morning until 3 in the afternoon. They can go one day per week or even up to 5 days per week. Some even provide transportation. Programs vary in quality so the caregiver will need to look for programs that attempt to provide activities to stimulate interest for the patient.
5. Memory care: Some families find it necessary to look into moving to an assisted living facility that provides memory care. Once again, the clinic can provide resources to help you begin the process of looking. It does require investigation and “shopping around” to find a facility that will meet your needs. Many of these facilities will even provide a temporary “respite” for a patient to stay for a short time in case the caregiver must travel or has an illness.
6. Prognosis: One of the most important aspects of having a diagnosis of dementia, or having a loved one with that diagnosis, is to understand the future. Not all dementias progress. Some, such as from a stroke or head injury, cause damage and the patient does not get worse. Indeed, they may even improve. However, most dementias in the elderly are from progressive illnesses, such as Alzheimer’s disease. Since most with Alzheimer’s disease are not even recognized as having the condition until they are already in a mild-to-moderate stage, most people are already several years into the condition at the time of diagnosis. As a rule of thumb, by the time most are 5-6 or more years into their symptoms they are often already requiring 24 hour-awake supervision. Thus, it becomes more than what most families can handle on their own and it becomes a great strain on personal and financial resources to keep the patient safe and cared for. Moreover, as the condition advances, the rate of decline usually accelerates, causing significant changes in behavior over a short period of time. At this point, families need to gather all of the information they can to understand this progression and resources they will need. An important resource at this stage is palliative or hospice care. Families need to ask early about how these services work as it greatly reduces strain on them and is of tremendous benefit to the patient when applied at the appropriate time.

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