Chapter 2
There Is No Such Thing As a "Little Dementia"!

Families frequently report that they have received the diagnosis of "a little dementia" for a loved one whose memory is impaired. There is no such thing as "a little dementia." It is like being a "little pregnant"—either you have it or you do not! And having "dementia" is never a good thing—although families who receive that diagnosis will frequently say, "Well at least it is not Alzheimer's!" This denial keeps them from learning about the disease, planning for a time when the loved one with the diagnosis is unable to survive without 24 hour care, and making other decisions that are best made before a situation becomes a crisis.

The words of the physician carry incredible weight with families. It is important for families to hear that the physician suspects that their loved one has Alzheimer's dementia and not "a little dementia." Minimizing the seriousness of Alzheimer's is a great disservice not only to the primary caregiver but also to the family. For many people "a little dementia" does not sound very serious and certainly not life changing. But Alzheimer's disease is both serious and life changing not only for the person with the diagnosis but also for the primary caregiver to the person whose memory is failing, as well as to other members of the family. The reality is that Alzheimer's disease always ends in death. If the person progresses through all the stages of Alzheimer's, the disease is fatal. There is nothing about it that justifies a description of "a little dementia." It is a terrible disease of the brain that leads to the complete loss of all the functions that we associate with being an independent adult. An honest diagnosis allows families to plan for the future, to get their financial affairs in order, to seek out sources of education and support, to know what resources exist in her/his community and how to access them, and to learn about the disease and strategies to manage the inevitable progression and decline (Carson 2011).

In the newly released *DSM-5,* physicians are instructed, for all neurocognitive conditions to specify whether the condition is due to Alzheimer' disease, frontotemporal lobar degeneration, Lewy body disease, or a variety of other brain conditions

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(American Psychiatric Association 2013). Are there other dementias that might also be linked to challenging behaviors? Of course there are and a brief description of selected dementias follows. But it is important to keep in mind that Alzheimer's dementia makes up approximately 65 % of all the dementias (Table 2.1).

Table 2.1 Common types of dementia

Alzheimer's disease (AD)	An estimated 5.2 million Americans have AD—including 5 million aged 65 and older or one in nine people aged 65 and older. Of those aged 75 or older, 44 % have it. One third (32 %) of those aged 85 and older have AD. Approximately 200,000 under age 65 have early onset AD
Vascular dementia (VD)	VD is the second most common cause of dementia after Alzheimer's disease, and is caused by "mini strokes" or occlusions of blood vessels in the brain. VD "paves the way" for Alzheimer's disease to develop, and VD/ALZ is a frequent diagnosis
Dementia with Lewy bodies (DLB)	People with Lewy body dementia often have memory loss and thinking problems similar to that seen in AD. However, the initial presentation of DLB includes sleep disturbances, hallucinations, and muscle rigidity or other movements that mimic Parkinson's disease. The brain changes of DLB alone can cause dementia, or these brain changes can coexist with the brain changes of Alzheimer's disease and/or vascular dementia, with each abnormality contributing to the development of dementia. When this happens, the individual is said to have "mixed dementia"
Parkinson's disease (PD)	As PD progresses, it often results in a progressive dementia similar to DLB or AD. Symptoms include problems with movement early on in the disease. If dementia develops, symptoms are often similar to DLB. The brain changes involve alpha-synuclein clumps that develop deep in the brain in an area called the substantia nigra. These clumps are thought to cause degeneration of the nerve cells that produce dopamine
Frontotemporal dementia (FTD)	Typical symptoms of FTD include changes in personality and behavior and difficulty with language. Nerve cells in the front and side regions of the brain are especially affected. Some people with FTD lose empathy for others as well as a sense of "what is appropriate" to say and do in public settings. Others lose language skills. There are no distinguishing microscopic abnormalities linked to all cases. People with FTD generally develop symptoms at a younger age (at about age 60) and survive for fewer years than those with AD

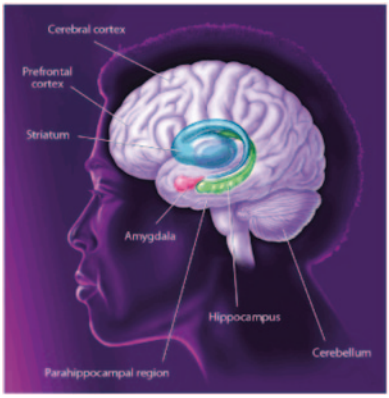
Table 2.1 (continued)

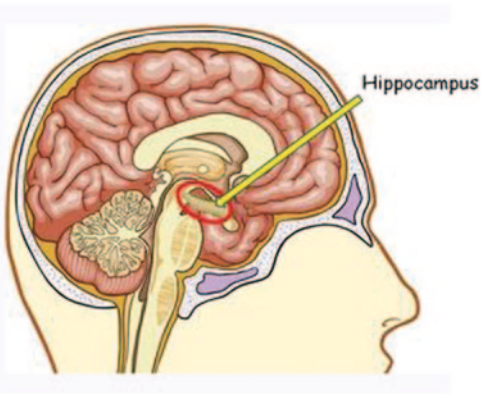
Creutzfeldt–Jakob disease (CJD)	Prion diseases such as CJD occur when prion protein, which is found throughout the body but whose normal function is not yet known, begins folding into an abnormal three-dimensional shape. CJD develops when prion protein in the brain also begins to fold into the same abnormal shape Through a process scientists do not yet understand, misfolded prion protein destroys brain cells. Resulting damage leads to rapid decline in thinking and reasoning as well as involuntary muscle movements, confusion, difficulty walking, and mood changes. Sign up for our enews to receive updates about Alzheimer's and dementia care and research CJD is rare, occurring in about one in 1 million people annually worldwide Experts generally recognize the following main types of CJD: Sporadic CJD develops spontaneously for no known reason. It accounts for 85 % of cases. On average, sporadic CJD first appears between ages 60 and 65 Familial CJD is a heredity form caused by certain changes in the prion protein gene. These genetic changes are "dominant," meaning that anyone who inherits a CJD gene from an affected parent will also develop the disorder. Familial CJD accounts for about 10–15 % of cases Infectious CJD is an especially rare form of CJD and results from exposure to an external source of abnormal prion protein. These sources are estimated to account for about 1 % of CJD cases. The two most common outside sources are: Medical procedures involving instruments used in neurosurgery, growth hormone from human sources or certain transplanted human tissues. The risk of CJD from medical procedures has been greatly reduced by improved sterilization techniques, new single-use instruments and synthetic sources of growth hormone The brain's patterns of electrical activity is similar to the way an electrocardiogram (ECG) measures the heart's electrical activity Brain magnetic resonance imaging (MRI) can detect certain brain changes consistent with CJD Lumbar puncture (spinal tap) tests spinal fluid for the presence of certain proteins Causes and risks Sporadic Creutzfeldt–Jakob disease has no known cause. Most scientists believe the disease begins when prion protein somewhere in the brain spontaneously misfolds, triggering a "domino effect" that misfolds prion protein throughout the brain. Genetic variation in the prion protein gene may affect risk of this spontaneous misfolding Mutations in the prion protein gene also may play a yet-to-be-determined role in making people susceptible to infectious CJD from external sources. Scientists do not yet know why infectious CJD seems to be transmitted through such a limited number of external sources. Researchers have found no evidence that the abnormal protein is commonly transmitted through sexual activity or blood transfusions

	Familial CJD is caused by variations in the prion protein gene that guarantee an individual will develop CJD. Researchers have identified more than 50 prion protein mutations in those with inherited CJD. Genetic testing can determine whether family members at risk have inherited a CJD-causing mutation. Experts strongly recommend professional genetic counseling both before and after genetic testing for hereditary CJD Sign up for our weekly e-newsletter Stay up-to-date on the latest advances in Alzheimer’s and dementia treatments, care and research. Subscribe now Treatment and outcomes There is no treatment that can slow or stop the underlying brain cell destruction caused by Creutzfeldt–Jakob disease and other prion diseases. Various drugs have been tested but have not shown any benefit. Clinical studies of potential CJD treatments are complicated by the rarity of the disease and its rapid progression Current therapies focus on treating symptoms and on supporting individuals and families coping with CJD. Doctors may prescribe painkillers such as opiates to treat pain if it occurs. Muscle stiffness and twitching may be treated with muscle-relaxing medications or antiseizure drugs. In the later stages of the disease, individuals with CJD become completely dependent on others for their daily needs and comfort CJD progresses rapidly. Those affected lose their ability to move or speak and require full-time care to meet their daily needs. An estimated 90 % of those diagnosed with sporadic CJD die within one year. Those affected by familial CJD tend to develop the disorder at an earlier age and survive somewhat longer than those with the sporadic form, as do those diagnosed with vCJD. Scientists have not yet learned the reason for these differences in survival Currently, the only treatment is supportive—there is no cure. Doctors may prescribe painkillers such as opiates to treat pain if it occurs. Muscle stiffness and twitching may be treated with muscle-relaxing medications or antiseizure drugs. In the later stages of the disease, individuals with CJD become completely dependent on others for their daily needs. The progression of the disease is rapid and results in the loss of the ability to speak or move, requiring complete full-time care
Normal pressure hydrocephalus (NPH)	Symptoms of NPH include difficulty walking, memory loss, and inability to control urination, which are caused by the buildup of fluid in the brain. NPH can sometimes be corrected with surgery
Huntington’s disease dementia (HDD)	HDD is a progressive brain disorder caused by a single defective gene on chromosome 4. Symptoms include abnormal involuntary movements, a severe decline in thinking and reasoning skills, and mood changes including irritability, depression, and others. The gene defect causes abnormalities in a brain protein that, over time, lead to worsening symptoms

Challenging Behaviors: Blame the Brain!

Another area that calls for honest discussion is the connection between challenging behaviors and specific brain damage. Why? Because without this knowledge, caregivers often arrive at the conclusion that their loved one with Alzheimer's is just being "difficult" and deliberately so! It is much more challenging to be patient with someone who seems to have some control over his/her behavior and is choosing to act in an unkind and difficult manner than it is to be patient with someone whose behaviors are directly linked to brain damage. Knowing that the behaviors result from brain damage removes personal responsibility from the patient—the behaviors naturally flow from what is happening in the brain and the behaviors are not deliberate attempts to frustrate or "get even with" the caregiver (Swaab 2014, pp. 348–351). Armed with knowledge connecting specific brain damage to specific behaviors allows caregivers to learn strategies to respond to these behaviors. It is not necessary for caregivers to have in-depth knowledge about the brain. A superficial, yet specific knowledge of how damage is linked to challenging behaviors is enough. Let us take a look at what level of knowledge is useful to caregivers. (Carson and Smarr 2007)





An area of the brain that is damaged very early on in Alzheimer's is the hippocampus shown in the picture on the left. This structure processes every experience that we have and stores long-term memories—sending the short-term memories to another part of the brain. In Alzheimer's, the brain becomes less and less able to process short-term memories, and since the "old" memories still remain, the person begins to "live" increasingly "in the past."

By stage 6 on the functional assessment scale (FAST) scale, the person has no more than 5 min of short-term memory and can only participate in one activity at a time. The lack of short-term memory means that questions are repeatedly asked and stories are retold. This is because the person asking the questions and retelling the

stories has no memory of having repeatedly asked the questions or told the same story. How can a caregiver calmly respond to this repetition? There are many ways that caregivers can make use of the person's deficits. If the activity is repetitive, mindless, and yet productive, the caregiver might redirect the person to participate in repetitive activities that he or she enjoys.

Folding towels or other laundry is an activity that most women have done repeatedly throughout their lives. It is mindless, repetitive, and productive. Asking a woman to fold laundry is a strategy that makes her feel productive and useful while at the same time redirecting her repetitive questions. And just as important, if the person is not asking the same question repeatedly, the caregiver will be more likely to remain calm and loving. There are many other activities that can serve to redirect annoying repetition into useful tasks—it only takes a little imagination, and the ability to recognize that disabilities can many times be abilities—given the right situation.

In contrast, a man who has Alzheimer's and engages in repetitive questions will most likely not want to fold laundry. However, he could be given a container of mixed coins and be asked to separate the coins into separate piles to be rolled and taken to the bank. He might manipulate Legos® and sort them by color or design and might even build with them. Keep in mind that the use of Legos® does not imply that the caregiver is treating this older adult as a child. If the caregiver knows the person's "story" then the interventions can be individually tailored to that person's interests. An example will clarify this.

> An elderly man was living with his son and daughter-in-law and they were both concerned over what they saw as Dad's failing memory, his repetition and other behaviors that were troublesome. They insisted that dad see a physician who specialized in geriatric medicine. That physician did a complete workup of this gentleman and concluded that the man was in the early stages of Alzheimer's, stage 4 on the FAST scale. The gentleman had been a wood carver since he was a young man. His carvings were quite beautiful and people used to pay a good deal of money to purchase one of his carvings. When the son and his wife received the diagnosis that Dad had Alzheimer's disease, one of their first questions to the doctor was, "Should we take away Dad's knives?" The physician answered them with an emphatic "no." He told them that the carving was second nature to their father and he would most likely continue to be safe for quite some time. He said "just watch him—you will know when it is time to take away his carving knives." Several years passed before the son and his wife needed to place Dad in an assisted living facility. They still did not stop his carving. His daughter-in-law kept him supplied with bars of Ivory soap and plastic knives and the gentleman continued to lean forward in a chair with a trash can between his knees and carve the bars of soap.

The hippocampus along with the parietal lobe is critical to mapping skills and safely traveling from one location to another. These areas of the brain sustain damage early on in AD and are reflected in people getting lost—not only in areas many miles from home but also in areas close to home where the person would be expected to "know his way." Becoming lost is a common and dangerous behavior frequently seen in those with Alzheimer's disease (Chiu et al. 2004). For example, the following story was reported in the periodical *Alzheimer's Reading Room* in 2012. This potentially horrific story had a happy ending because two dedicated and kind police officers went "above and beyond the call of duty" (http://www.alzheimersreadin-

groom.com/2012/02/alzheimers-patient-lost-wanders-1500.html). Here is the cliff notes version of this story:

- *An unnamed man suffering from Alzheimer's managed to get on a bus in Virginia and traveled to Denver, Colorado.*
- *Someone discovers the man who at this point is disoriented, out of cash, and unable to cash a check.*
- *Next, police officer Hana Ruiz comes on to the scene.*
- *Police finally figure out his name by referring to his checkbook and are then able to contact his caregiver through the bank.*
- *Money is wired to buy him a plane ticket home.*
- *Happy ending right? Not yet.*

Next:

- *Officer Ruiz dips into her own pocket to buy him food, and gets him a place to stay.*
- *The next morning, Officer Ruiz asks Officer Rob Martinez to help get the man dressed and to the airport on time. Understandable.*
- *Officer Martinez notices that the man's cloths are in poor condition so he buys him new clothes. Officer Martinez also dips into his own pocket to do this.*
- *They take the man to the airport.*
- *Happy ending right?*
- *Not exactly, the man for some unknown reasons cannot get on the plane.*

Next:

- *Officer Ruiz dips into her own pocket to buy the man a bus ticket home.*
- *She then finds someone to accompany him home. Whew, great idea. If not, this story would probably have a part 2, 3, and 4.*
- *Finally, the two officers use their own money to make sure the man has food for the long trip home; and then, assured that his caseworker was waiting to pick him up in Virginia*.

Officers Ruiz and Martinez received the "Citizens Appreciate Police Award" (DeMarco 2012).

Because "getting lost" is such a common behavior among those with Alzheimer's, caregivers are encouraged to enroll their loved one in the Medic Alert + Safe Return program offered by the Alzheimer's Association. This program sells a *Medic-Alert* bracelet for the person with Alzheimer's as well as for the primary caregiver. If the person with Alzheimer's or a related dementia wanders and gets lost, caregivers can call an emergency response line (1-800-625-3780) and report it. A community support network is activated including law enforcement and members of the local Alzheimer's Association Chapter to assist in the search for the missing individual. If the person with Alzheimer's is found by someone other than the family or the police, he/she can call the toll free number listed on the back of the bracelet and Medic Alert + Safe Return will notify the person's contacts and make sure

that the person is safely returned home. The necessity for the Medic Alert bracelet for the primary caregiver is best illustrated with another story.

> A daughter was caring for her father; they lived in a small suburban community in Michigan. One morning the daughter realized she needed to purchase a gallon of milk. She decided it was easier to go to the local super market without her father. Unfortunately she did not anticipate that she would be involved in a serious accident that would result in her hospitalization. Her car was struck by a large truck and she sustained life threatening injuries. Fortunately she was wearing her Medic Alert bracelet that identified her as a caregiver to someone with Alzheimer's disease. The hospital staff dispatched an ambulance to go to the daughter's home and pick up her father who was temporarily placed in an Assisted Care Facility until his daughter fully recovered from her injuries. (Story shared with Dr. Carson 2008)

Today, there are a variety of devices that utilize GPS technology so that the movements of the person with Alzheimer's can be tracked. Some states issue "Silver Alerts" which serve as a public notification system that broadcasts information about missing persons—especially seniors with Alzheimer's disease, other types of dementia or other mental disabilities—in order to aid in their safe return.

Silver Alerts use a wide array of media outlets—such as commercial radio stations, television stations, and cable TV—to broadcast information about missing persons. Silver Alerts also use variable-message signs on roadways to alert motorists to be on the lookout for missing seniors. In cases in which a missing person is believed to have gone missing on foot, Silver Alerts have used reverse 911 systems to notify nearby residents of the neighborhood surrounding the missing person's last known location.

The activation criteria for the Silver Alert system vary from state to state. Some states limit Silver Alerts to persons over the age of 65, who have been medically diagnosed with Alzheimer's disease, dementia, or similar mental disability. Other states expand Silver Alert to include all adults with mental or developmental disabilities. In general, the decision to issue a Silver Alert is made by the law enforcement agency investigating the report of a missing person. Public information in a Silver Alert usually consists of the name and description of the missing person and a description of the missing person's vehicle and license plate number.

Return to the diagram of the brain and look at the diagram on the left. The hypothalamus is located in close proximity to the hippocampus. The hypothalamus controls appetite and body temperature. At the beginning of stage 6 on the FAST scale, the person is hungry all the time, despite the size of the most recent meal! The hypothalamus stops sending signals of "fullness" even after eating a large meal. The person not only feels hungry but because of damage to the hippocampus the person may have no memory of recently having finished eating. The person will repeat "When are we going to eat?" over and over again. The caregiver needs to be instructed to make available healthy finger foods such as cheeses, fruit, vegetables, and pieces of meat and to encourage the person with Alzheimer's to graze throughout the day. If the person gains weight this is not a problem. If the person has diabetes and there is concern about blood sugar levels, this can also be managed. The reason is that as the person reaches the end of stage 6, the hypothalamus will stop sending signals of hunger so that the person will not want to eat and can lose as much as 20–30 % of their total body weight. A little extra weight will be a good thing when the person reaches the stage when refusal to eat is common. One of the

strategies to encourage continued eating in the end stage is to puree food mixed with chocolate syrup or jelly, since many people with Alzheimer's retain their taste for sweets.

Let us look at what happens to body temperature in someone who has Alzheimer's disease. People with this disease are cold all the time—even when the ambient temperature is set high. The person might be wearing layers of clothing, knit booties on his/her feet, covered with a lap blanket and still complaining vociferously about the cold temperature. This has significant implications for bathing. The person who will be bathing another person needs to build up a head of steam in the bathroom so it is warm in there, and towels and clean clothes need to be warmed before offering them to the person.

What about the limbic system, the center for emotional control? As the limbic system sustains increasing damage from Alzheimer's, the person will gradually show symptoms of being on an emotional roller coaster. She is happy 1 min and then without any apparent external provocation she is angry or teary eyed! The response of the caregiver needs to be comforting and patient towards the loved one. However, the patient does not "own" this behavior. Without knowledge that this rapid change in moods is caused by brain damage, the caregiver might be very perplexed to understand these emotional changes and might assume unnecessary guilt for inducing them.

What about the occipital lobe? Damage to the occipital lobe can result in visual agnosia. In other words, people see an object but their brains no longer can interpret the purpose of the object. For instance, a person with Alzheimer's might pick up a toothbrush and try to brush his/her hair with it. Or, a person might think that the television remote control is a telephone receiver. It is not that the person cannot "see" the object, but that his/her brain can no longer identify its use.

The last area of the brain that can be damaged by Alzheimer's is the frontal lobe which can lead to behavioral dysregulation resulting in behaviors such as saying or doing things that might be considered threatening, bizarre, or generally inappropriate. Examples of these behaviors might include swearing, undressing, urinating in public, eating and drinking nonfood items and others—all very difficult for caregivers to manage. The frontal lobes are essential to planning, organizing, and creating structure in our days—these are skills that are lost in Alzheimer's.

In the next chapter, we will take a look at pain—a condition that is largely ignored in those with Alzheimer's disease. Because pain is frequently not recognized, those with Alzheimer's may receive antipsychotic medications that may or may not be appropriate.

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