STUDY GUIDE

Alzheimer’s Disease, 300 Tips for Making Life Easier

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A person’s brain weighs only about three pounds and yet it is the most important part of the body. In a healthy, productive person, all parts of the brain work together allowing the individual access to key brain functions which include:

1. Access to long and short term memory
2. The ability to utilize language—both verbal and non-verbal
3. The ability to complete complex tasks
4. The ability and capacity to engage socially with others
5. The power of judgment and reasoning
6. Use of a full range of bodily movement
7. Use of his/her senses to see, feel, hear, taste, smell, and have the ability to integrate information.

When a person’s brain is healthy and has been kept active, long-term and short-term memories can be recalled through concentration and focus. Memory cues include: a) sight, smell, taste, sound b) sensations c) people d) places e) objects.

A healthy brain is able to understand sounds and engage in the complex task of communicating effectively with others. Good communicators recognize and use proper verbal and non-verbal cues. They read the signs of discomfort, stress, frustration as well as pleasure, enjoyment and a sense of well-being in others. They are active listeners and respect the other person’s point of view.

The Key Functions of the Brain in the Pre-Alzheimer’s Stage

1. Memory
2. Language
3. Complex tasks
4. Social Skills
5. Judgment and Reasoning
6. Ambulation
7. Senses

From time to time in our lives we can experience a decrease in one or more of the key brain functions. We forget someone’s name or momentarily are at a loss for words. We find that it takes us longer to do things that once came so easily. Sometimes these losses can be due to stress, lack of sleep, physical ailments, or even mild depression and treating these problems can help us get back to normal.

A characteristic of the normal aging process is that general intelligence, which medical scientists call “psychomotor functioning” or “cognitive functioning” remains normal and reasoning abilities and judgment are not altered.

Symptoms of Alzheimer’s disease are actually much more problematic than just the simple lapses in memory, and these symptoms begin to interfere with the ability to perform normal activities. The changes are not sudden, but slowly and progressively become more apparent over many months. No single behavior can be called characteristic or diagnostic of Alzheimer’s disease. However, an individual who has several characteristics of these behavioral symptoms likely is experiencing something other than just the normal brain aging process. That “something” could well be dementia, which is the scientific term used to describe the progressive loss of intellectual abilities as seen in Alzheimer’s disease. However, Alzheimer’s disease is only one of many brain conditions that can cause dementia.

Alzheimer’s disease causes the progressive of nerve cells in the cerebral hemispheres of the brain. The progression of the disease can last for a period of 8 to 20 years, depending on the unique circumstances and health of each person affected.

Although there are commonalities, each individual affected with Alzheimer's disease or related dementia experiences the disease uniquely; the disease progresses at its own rate and the deterioration does not occur in a lock-step, uniform pattern.

When talking about Alzheimer's disease, it is helpful to divide the progression of the disease into stages so that care of individuals can be more easily understood. Although the progression of Alzheimer's disease can be divided into many stages, this book collapses the categorization into just three stages.

1. The Early-to-Mild Stage

2. The Moderate Stage

3. The Severe Stage

These divisions are like describing the "stages" of a child's growth and behavior during the child's first year, second year, (terrible two's) teenage years, etc.

As the disease progresses' the person with Alzheimer's disease gradually loses brain functions and in many ways begins to demonstrate behaviors that are more childlike. "Staging" of the illness serves the purpose of providing guidelines for making plans for continuous care. Even though nerve cells are lost throughout the progression of the disease, some functions remain during all stages. Dr. Roger Brumback shows the progression of the disease and the functional skills.

The Progression of Alzheimer's disease in the Brain by Roger Brumback, MD

What happens in the brain during the Early-to-Mild Stage (generally in 3–5 year period)?

The first area in which the nerve cells die as a result of Alzheimer's disease is the memory area of the brain. Because judgment, reasoning, and social skills are still functioning normally, the person can develop compensatory coping strategies to deal with the memory problems. Thus in the beginning stage of the disease process, no one will be aware of the problem because of theses compensations.

What happens as the disease progresses toward the Moderate Stage (generally a 3-5 year period)?

The wave of nerve cell destruction spreads through the brain. In this stage, the individual has trouble dressing, gets lost or disoriented, and cannot figure out how to use objects, and driving does become problematic. This is the time when a person generally consults a doctor for an evaluation and family and friends become aware of the problem.

What happens as the disease progresses into the Severe Stage?

The person loses the ability to interact properly. This is the stage at which a person often can no longer be managed by family/caregivers at home. The person loses judgment, reasoning and social skills. Since the median survival is 7 years after diagnosis, an individual may die before reaching the Severe Stage of the disease.

Survival during the Severe Stage depends a lot on the quality of nursing care, since patients lose many of the self-care functions that prevent other illnesses. Alzheimer's disease is the underlying cause of death; that is, it weakens the brain's control of body systems and allows other illnesses to end the patient's life.

Every person diagnosed with Alzheimer's disease or a related disorder has individual rights throughout all the stages of the disease. Reflecting on these rights can help caregivers adjust their care giving to recognize the person's dignity throughout the progression of the disease.

It helps to remember that not all the key brain functions will diminish at the same time, and when we forget or fail to acknowledge the remaining functions, negative actions can become part of our care giving style. For example, we may speak to persons with Alzheimer's disease as if they were a child or simply ignore them.

When we look for the dignity within persons who have Alzheimer's disease, we look for ways to help them compensate, cope, and adapt to their ever-changing life. Everyone wants to be treated with dignity and respect. Here are some examples of persons with the disease and their self-reflecting:

- A clinical nurse with Alzheimer's disease shared: "I've lost my memory but not my mind. Because of my profession I can reflect on myself as a patient and see what is happening sometimes"
- A business man who used to work in a Fortune 500 company stated: "I use to manage many things. I still want to do what I can do. Please don't give me envelopes to lick and thing that fulfills me."
- A former professor at a university reflected: "I don't understand why they won't let me go to church alone, It's just across the street. I use to teach in foreign countries, I know how to get to places."

As Alzheimer's disease progressively consumes brain function, those that remain must be cherished and with care giver's assistance, displayed more prominently. The first symptom noticeable in the Early-to-Mild Stage is memory loss. The rest of the brain works normally, however, so the person still moves, and feels things, sees, hears, and integrates information.

Alzheimer's disease will first impact a person's short-term memory. Something important for the care giver to remember is that persons with the disease generally also know they are losing their memory. If possible, early in the disease process, identify those things that are really important. Activities that are habitual will still be possible and can help the person with dementia feel productive.

Language also begins to deteriorate in the Early-to-Mild Stage, so that conversations with a person with Alzheimer's may become more difficult. Finding the right words to fully express what they are feeling can be problematic.

A person with dementing illness depends on a certain amount of structure in daily routines. This consistency is important in helping to minimize the amount of stress they experience. Multistep tasks that might have been readily preformed in the past now need to be broken into separate individual tasks. Ambulation will start to become a problem. They show up slowly, and come and go depending upon the circumstances. For example: while waiting in line, taking a few steps forward and then stopping can become confusing. A nurse once said, “Think of Alzheimer’s disease like a piece of Swiss cheese; sometimes there is great clarity and the person can see through the holes; other times things are cloudy and the person cannot understand or reflect.”

As the disease progresses to the Moderate Stage, the destruction spreads over the parietal lobes of the brain. When this occurs, the person loses the ability to integrate visual, sounds and body sensation information. At this stage, the individual has trouble dressing, gets lost or is disoriented, and cannot figure out how to use objects. The person generally has great difficulty asking for things, or for help, because the destructive process of the disease has already devastated the temporal lobe speech areas.

Behavior problems, such as wandering and agitation, may occur at this time and the person needs more intensive supervision. It is not unusual for agitated behavior to become worse later in the day or early evening. Reflect on the way you respond to the person; if the person becomes combative, ask yourself these questions: “am I in any danger?” “Can I handle this situation?” Often, you can avoid harm by simply taking five steps back and standing away from the person for a short time. Keep in mind that at this stage it can be difficult because the person no longer remembers thoughts long enough to express them or recall questions long enough to answer them.

Although short-term memory may have disappeared, long-term memory may be intact. Many times persons in the moderate stage of the disease become angry or agitated because they do not understand what is expected of them. They may be frustrated by their inability to make themselves understood. Be aware that some people at this stage may repeat the same sounds or statements or revert to their original language when trying to communicate. Also they may insert the wrong word in a sentence. For example; the person may state, “I want to eat my hair”, instead of, “I want to comb my hair.” Do not make a big deal about correcting him/her.

Never argue with a person with dementia, they will only become angry, more confused and frustrated. Try to always approach the person slowly and face them when speaking. Pause between sentences and allow plenty of time for the information to be understood. Use short sentences, express one main idea, and use eye level when you speak.

In the Severe Stage, the capacity to deal with anything complicated is diminished. Bodily functions become weak and are failing. Comfort and cleanliness is of great importance.

In this Severe Stage of Alzheimer's disease, the devastation moves into the frontal lobes. Once the frontal lobes are damaged, the person loses the ability to interact properly. They lose judgment, reasoning, and social skills and at this stage respond inappropriately and unacceptably having lost much of their, "civilized" behavior.

Also in the Severe Stage of Alzheimer's disease, many of the brain functions have been consumed. Rather than focus on what is missing, care givers can focus on helping maintain the remaining functions. At varying times in the frontal lobe stage, the person can be violent with rages or docile, apathetic, and immobile. For example; touching, such as helping the person to undress, can trigger violence to repel the contact, possibly injuring either the care giver or the person with the disease.

In the end stages, the destructive Alzheimer's disease process has killed nearly all the nerve cells of the cerebral hemispheres except the strip of motor cortex and the visual cortex, which is why in nursing homes, the main activity seems to be walking and pacing. By now long-term memory has failed, however, it is still possible to trigger some memory with pictures and sounds. Communication will be very difficult and it will be hard to determine how much comprehension remains. Never assume the person does not understand your words of comfort and assurance even if they don't respond. In the final stages, even these brain areas are destroyed, and the individual will become bedridden and relatively unresponsive. The plaques and tangles (hardened areas of brain tissue that are the physical traces of the disease process) are widespread throughout the brain.

Case Study:

My father lived at home alone until he was 95. Through the Early-to-Mild Stage, I was able to get local resources to come to Dad's home. I used the local Alzheimer's Association chapter. The visiting Nurses Association equipped dad with an electronic emergency call system for him to wear throughout the home. I called my dad twice a day to monitor his activities. After a stay in the hospital because of a urinary tract infection, physical therapy professionals said dad should not be home alone because he could not remember to put his hands on the arms of the chair in order to lower his body into it. He couldn't remember the process and would fall backwards to sit down.

The first move from home to an assisted living facility that knew how to care for persons with dementia was painful for dad, me and my husband. My father did not understand why he needed to leave his beloved home.

After about six months the assisted living facility became home to my dad. He began to have more serious urinary tract infections and developed trouble swallowing. After another stay in the hospital it was decided that he needed a special diet so that he could continue to eat.

The assisted living facility could not keep Dad, because “assisted living” means that the person can function without a special diet or the need of assistance in self-care.

The next move was from the assisted living facility to a well-respected Nursing Home and Rehabilitation Center. The move from the assisted living facility where my dad was used to having his privacy to the shared bedroom was another difficult move.

The living situation did not turn out to be what we had hoped. Dad’s greatest pleasure during the day was having a window to look out. Dad loved the window next to his bed because he could watch the parking lot and the people go by. I still wanted to move him to a private room, but it we could not afford it. There were no rooms available for him with the window view.

More infections entered my father’s system, and one day the nursing home called me to have dad taken to the hospital. At the hospital, physicians found that my father has five different infections. One of them was severe enough that his frail body could not combat it. After a week in the hospital, the family physician met with us and told us that there was nothing more the health profession could do and that the infections would persist until dad’s death.

Through dialogue with the doctor it was decided that dad would move to Hospice House. My father stayed at Hospice House for about 2 months. Hospice care is for comfort until death. Gradually, my dad moved into the last part of the Severe Stage. He had volunteers to feed him when I could not be there. I knew my dad was being treated with the respect and dignity he deserved. I was with him at his death, which was quiet and peaceful. Hospice House and volunteer organizations were lifelines for Pat and her husband.

In conclusion, there is a saying, “If you’ve met one Alzheimer’s resident-you’ve met one Alzheimer’s resident.” While not particularly humorous, the saying puts into perspective what should be intuitive when considering all aspects of the life of the person with Alzheimer’s disease, including the living environment. Whether it is an individual’s home or communal living arrangement (Assisted Living or Nursing Home), it is actually an environment for an “Individual”.

Key Basic Tenets are necessary to make the environment appropriate for the person with Alzheimer’s disease; independence, choice, security, privacy, companionship, stimulation, and rhythm. Creatively modifying the environment for the individual, and varying it as the disease progresses, it vital to utilizing the environment to maximize the potential of persons with Alzheimer’s disease.