

Loss of Initiative

Personality type, individual propensities and location in the disease process must all be taken into consideration when examining if a person's unwillingness to participate in life's activities is due to loss of initiative, their decreased comprehension abilities or depression. Often seen pre-diagnosis, loss of initiative is a symptom that causes individuals with AD to show less interest in daily tasks and activities, and even in the lives of others. The person may become very passive, sitting in front of the television for hours, sleeping more than usual, or not wanting to do activities they previously enjoyed. Observing such dramatic changes in a loved one can be very difficult and distressing. While the person is still able to participate in daily tasks and activities, a solution for loss of initiative is to build a structured routine based on the passions and joys of the individual, utilizing skill-level appropriate activities. It is crucial to keep in mind that as the disease progresses, the damage to the brain increases, further inhibiting the person's abilities and eventually resulting in a true loss of ability to perform tasks. The following information is taken from "Early Access to Support and Education for Persons with Alzheimer's Disease" by Mary Keenan, Psy. D.

Persons with Mild AD have symptoms of memory loss and difficulty learning and recalling recent information. Many, though not all individuals, are aware that they are not remembering or thinking as well as they used to. Most individuals with Mild AD are able to compensate for the cognitive changes they experience, sometimes so well that their disease goes undetected for some time. The detection of Mild AD is complicated by the fact that most persons with Mild AD maintain their social skills, though some may not be as interested or comfortable socializing as they were prior to the onset of the disease. Individuals with Mild AD do not require assistance caring for their basic personal needs. However, minor assistance or supervision is needed with complex instrumental activities of daily living such as money management or the administration of medications.

According to Keenan, an individual with Mild AD may develop depression or appear apathetic. Apathy, an attitude of indifference, is both a symptom of depression and a non-memory feature of AD. For people who are depressed, apathy is often associated with feelings of hopelessness about the future, a sense of helplessness, self-deprecating statements, tearfulness, a loss of energy, or anhedonia (i.e., an inability to take pleasure in once enjoyable activities). In AD, apathy doesn't develop as a result of sadness or emotional distress. Rather, AD-related apathy is the result of changes in higher-level cognitive processes such as reasoning, judgment, insight, planning, and organization.

In addition to potential cognitive and interpersonal barriers, the presence of apathy due to Mild AD prohibits individuals from structuring their free time. Evidenced as a lack of interest or motivation, apathy may occur as a non-cognitive feature of Mild AD and compound problems associated with diminished initiative. Depressed individuals some-times experience apathy as a feature of mood disorder. A careful clinical evaluation can determine whether apathy, if present, is due to disease-related cognitive changes or the presence of depression.

It is possible to have both depression and AD at the same time. Individuals with AD may develop depression as a neurochemical or psychosocial consequence of the disease. Moreover, the presence of depression may magnify the cognitive symptoms of AD. Someone with Mild AD who becomes depressed may appear more apathetic, socially withdrawn, forgetful, confused, or indecisive. Because individuals who are depressed perform differently on neuropsychological testing than those with AD, it is possible to determine whether an individual's thinking and memory problems are due to depression or dementia.

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However, if someone presents with depression and co-existing memory problems, it may not be possible to immediately determine if the memory problems are due solely to the mood disorder or whether there is an underlying dementia present as well. To make this determination, the physician will often make a referral to a psychiatrist or elect to treat the mood disorder with antidepressant medication herself to ensure that the patient receives maximal treatment of their depression. If the emotional or vegetative symptoms of the mood problem are alleviated with anti-depressant medication, but the individual's cognitive problems remain, then a dual diagnosis of depression and dementia is made.

Routine and Activities

Having a daily routine in place naturally helps someone with Mild AD compensate for changes in thinking and memory. Without structure, the risk for under stimulation, restlessness, boredom, or daytime napping increases, all of which may jeopardize quality of sleep for both patient and care partner. The person will need assistance creating and following the routine. If there is an existing routine, promote structure by modifying it. Try to adhere to an established time schedule. Strive to go to sleep and wake at the same time each day, dine regularly, and schedule recurring activities of interest for the same time each week. Doing so will help compensate for problems with recall or orientation to time.

Regularly occurring activities should continue or increase in frequency provided the activities are appropriately stimulating and meaningful for the patient. For example, if someone participates in a birthday lunch group one a month, supplement that by arranging weekly scheduled lunches with individual members of the club, former co-workers, longtime friends, church members, family, or any combination of the above.

New activities should be assimilated into an existing schedule to accommodate individual preferences and unanticipated opportunities of interest.

In instances where work took priority over recreation, outside interests or hobbies may never have been developed. These hard-working individuals with Mild AD are suddenly charged with the difficult task of learning how to recreate. They must learn how to individually define and value recreational activities at the same time the ability to learn new information is impaired by their medical condition. Encouraging someone with Mild AD to "take up a new hobby" without providing the necessary structure or supervision for the activity to take place often results in feelings of frustration for the patient and the care partner. Similarly, encouraging someone to continue in or resume previous interests may be unrealistic if those activities are highly memory dependent or cognitively complex.

If an activity becomes too difficult or is no longer rewarding, or, for reasons of safety must be discontinued, it should be replaced with another. Individuals with Mild AD may enjoy physically challenging activities, which promote overall wellness and reduce their risk for other diseases, which might negatively impact the management of their AD. Activities, which provide fellowship and an opportunity for social interaction, are ideal as long as there is sufficient structure and supervision when needed. Activities, which rely heavily on memory for success or require the person to learn new information, are not the best choice.

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When first developing a daily/weekly activity schedule with someone, think broadly. Generate a list of all possible activities to fill the day. Then, critically review the list and select which options are feasible. The resulting schedule should be predictable, appropriately challenging, and consist of activities that provide a sense of purpose and meaning:

1. Avoid the misconception that an activity must be “cognitively challenging” to be of value (e.g., crossword puzzles, brain teasers, computer games, jeopardy, etc...). Inherently, AD transforms most activities into cognitively challenging tasks.
2. Emphasis should be placed on those activities that capitalize on an individual's current strengths, abilities, and interests. Individual interests may change as a function of AD. What may have been enjoyable at one time may no longer be satisfying or pleasant to the individual over time. Be flexible.
3. Carepartners should avoid predetermining someone's involvement in an activity based on their own preferences or predictions of whether the patient will like it.
4. If someone cannot continue an activity in a leadership role due to their AD, it does not mean attendance at the activity must be abandoned. Relieved of the pressure of performing publicly, many individuals enjoy their “retirement” and new status as a group member or individual “mentor” for younger people in their group. Suggesting someone “pass the baton” and transition into a membership or mentor role is one strategy for helping someone step down from a position of authority when necessary.
5. Pursue activities which are non-memory dependent. Customize activities to capitalize on individual strengths and rely on areas of cognition which may be initially very resistant to the presence of disease. For example, activities which promote social give and take, musical appreciation, creative or artistic expression, humor, or dance/physical activity/exercise, may all be viable options. Balance passive or solitary activities (e.g., watching movies or television) with those requiring more active participation.
6. Consider participating in specialized programs designed for persons with Mild AD. The Alzheimer's Association Chapter in closest proximity should be contacted about options such as day activity/wellness programs, support groups, dance/art therapy courses, organized social/recreational community groups, or supervised volunteer opportunities.
7. More often than not, individuals with Mild AD are much more likely to undertake a new activity if accompanied by a trusted other. Sometimes this is the primary care-partner. Alternatively, this might be a trusted friend, former co-worker or employee, neighbor, church member, or paid companion.

Resource

Keenan, Psy.D., Mary. Early Access to Support and Education for Person's with Alzheimer's Disease. Alzheimer's Association, Capital of Texas Chapter. 2008.