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# Discharge Planning and Managing Early Alzheimer's Disease

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**D**evastating. This is the single word that most commonly and completely describes the reaction of patients and their family members to a diagnosis of Alzheimer's disease (AD). The memory loss, difficulty with decision-making, slow decline in activities of daily living (ADLs), behavioral symptoms, and eventual death associated with the disease present a bleak future prospect for AD patients and their caregivers.

There is no cure for the disease yet. Nonetheless, there is much that can be done in assisted living and other settings to lessen the fear, stress, and burdens that accompany AD. These interventions start with early assessment, access to available support services, and detailed, comprehensive plans of action and appropriate plans for care.

## **Background: Gaining Control of a Daunting Problem**

As the numbers of Americans with Alzheimer's disease will grow to as many as 16 million by 2050,<sup>1</sup> there is a serious need to address social, care, and support issues related to this conditions. Non-paid caregivers in home settings need training, support, and respite; and safe, cost-effective alternatives to institutionalization will be necessary. It also will be imperative on the elder care

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system to assess and identify the onset of AD as early as practically possible to successfully manage the condition, maximize outcomes, and keep costs in check.

Early and reliably accurate assessment will lead to better planning and resource allocation. It also will promote better long-term quality of life and more effective care planning—both in the community and in senior living and long term care settings.

### Surveys Show Scope of Assessment Needs

Results from a recent series of surveys by Stackpole & Associates of professional caregivers working in senior living and long term care clearly show a need for better assessment and care planning skills. It also indicates that many individuals with AD are being institutionalized prematurely or even unnecessarily.

The surveys were part of an educational program for caregivers, in which participants were invited to be part of pre- and post-program questionnaires. The results of the pre-program surveys suggest the scope of the work that still needs to be done for assessment and care planning (see Table 1). For example, participants indicated that up to 50% of the residents in their care were diagnosed with AD, but other residents had AD who had no such diagnosis in their medical records. Seventy to ninety percent (70-90%) of participants reported that there were residents with AD in their care who had not been diagnosed. This suggests significant under-reporting of the illness, which raises the question of why these residents are not being assessed and diagnosed.

### Return to the Community: Mission Impossible?

The study looked at the relation-

Table 1.  
Survey Results

|  |         |
|--|---------|
| % of residents in skilled nursing facilities diagnosed with Alzheimer's Disease                    | 10–50%  |
| % of participants reporting residents with undiagnosed Alzheimer's disease                         | 70–90+% |
| Prevalence of Mild Alzheimer's in Skilled nursing facilities                                       | 10–17%  |
| Prevalence of Moderate Alzheimer's in Skilled Nursing Facilities                                   | 20–15%  |
| Prevalence of Severe Alzheimer's in Skilled Nursing facilities                                     | 25–35%  |
| % of participants reporting no suitable discharge options for return to the community              | 45–60%  |
| % of participants reporting more residents could be discharged if discharge options were available | >50%    |

**A striking 50% of survey participants reported that if discharge options were available, more patients with mild to moderate AD could be returned to the community.**

ship between care planning and stages of AD. Participants reported that 10-17% of their residents had "mild" AD and 20-50% had "moderate" disease. Many caregivers believed that there were no suitable discharge options back to the community for AD residents. Approximately half (45-60%) of caregivers stated that newly admitted residents with AD have no written discharge plans; yet a striking 50% reported that—if discharge options were available—more patients with mild

to moderate AD could be returned to the community.

It is not particularly surprising that facilities seldom have or develop plans to return residents with AD to the community. There are many obstacles to successful discharge of these residents, including:

- advancing age of the spouse or caregiver
- need for the caregiver to work outside the home
- cost of paid caregivers, averaging \$12,500 per year<sup>2</sup>
- emotional and physical toll on caregivers
- fear the caregiver has in assuming increased responsibilities
- fear on the part of caregivers that they will fall victim to the disease

Addressing these barriers can be challenging. It requires strong communication and collaboration between various teams and departments within the facility and relationships between facilities and community resources and organizations.

Of course, one answer to this situation is a monetary one; and a Congressional task force is examining increased federal funding for research and financial support to help with medications, day care, and respite care. However, only an improved understanding and

awareness of support options, better tools for early and reliable assessment, and comprehensive care plans to maintain functionality truly can make community care a reality.

## Steps to Better AD Care Planning

The best approach for facilities is to have a clear process in place for assessing and managing residents with AD. It also is important to ensure that staff—as well as practitioners caring for residents—understand the process and their role in it.

This process should start with an assessment that rules out all other medical problems or medications that may be causing the resident's dementia. Assessments for AD should include a variety of activities and tools, such as:

- Patient history
- Physical exam
- Laboratory tests
- Computed Tomography (CT or CAT) scan
- Magnetic Resonance Imaging (MRI)
- Electrocardiogram
- Neuropsychological testing
- Positron Emission Tomography (PET) scan
- Single Photon Emission Computed Tomography (SPECT) scan
- Magnetic Resonance Spectroscopy Imaging (MRSI)

Five areas require assessment and reassessment in AD patients. These are:

- Daily function (assessment of ADLs)
- Cognition (use of Mini-Mental State Exam)
- Comorbid medical conditions (assessment of conditions such as cardiovascular disease, infection, pulmonary disease, renal insufficiency, and arthritis)
- Emotional and mood disorders (periodic assessment for depression, agitation, and psychotic symptoms)
- Caregiver status (determination of

## Table 2. Alzheimer's Disease Resources

There are many resources—national, regional, and local—to help patients and families deal with Alzheimer's disease. Here are just a few:

- **Alzheimer's Association:**  
[www.alz.org](http://www.alz.org)
- **Alzheimer's Disease Education and Referral Center:**  
(Educational materials and publications for patients, caregivers, and health care professionals; information about clinical trials; and more):  
[www.alzheimers.org](http://www.alzheimers.org)
- **National Adult Day Services Association:**  
[www.nadsa.org](http://www.nadsa.org)
- **Medline Plus:**  
(Alzheimer's Disease) (Links to news, educational materials, disease overviews, and other resources for patients, caregivers, and health care professionals):  
<http://nihseniorhealth.org/alzheimersdisease/toc.html>
- **National Family Caregivers Association:**  
[www.nfcacares.org](http://www.nfcacares.org)
- **Alzheimer's Resource Center:**  
<http://www.healingwell.com/alzheimers/>
- **Alzheimer's Resources:**  
(for Patients and Families):  
<http://www.alzheimersresources.org>
- **Caregiver Information:**  
[www.caregiver-information.com](http://www.caregiver-information.com)
- **ElderCare Online:**  
(Comprehensive information, education and support for people caring for aging loved ones with dementia: special programming on all aspects of eldercare):  
<http://www.ec-online.net>
- **Empowering Caregivers:**  
(Features emotional and spiritual support, columns, articles, forums, chat groups, humor, and more):  
<http://www.care-givers.com>

available assistance and support)

When an AD diagnosis is made, discharge plans should be initiated for the resident. This planning must begin with education for the patient, caregivers, and others family members. This education should include referrals to community resources—such as support groups—for family members who will be helping to care for the individual with AD.

Understanding the cause of the disease, its gradual progression, and typical presentation and symptoms will enable the creation of personal action plans that support individuals with AD and their families for as long as possible. It is important to remember that residents and their families likely have heard a great deal about AD and may have misperceptions and unfounded fears. Social workers

and clinicians can work together to make sure that residents and their families have accurate information about the etiology of the disease and what treatments might be useful. This will require asking about fears and concerns and addressing these directly through educational materials, counseling, and other means.

Decisions will have to be made about whether or not the individual will continue to work, drive, seek help with financial and legal planning, and make physical improvements to the home to accommodate future needs. Continued physician visits will allow the doctor and the support team to assess the progress of the disease from baseline and make adjustments in clinical interventions over time. Different assessment tools that go beyond memory testing may be

needed over time to assess ADLs and depression. This likely will require the resident's family physician to coordinate care with other medical specialists—ranging from neurologists to counselors.

Of course, there will be other issues that must be addressed with each resident and his or her family members. These include decisions about whether it is safe and appropriate for the individual to continue to work, drive, handle finances, and maintain his or her home. Clinicians and facility staff should be prepared to collaborate with community resources to get individuals with AD and their families the support, assistance, and guidance they need. Many hospitals offer educational programs and support groups, and the Alzheimer's Association has established a network of local groups across the country to assist in dynamic emotional, clinical and mental needs. Table 2 lists some

resources for people with AD and their families.

One important point clinicians should emphasize to the resident, caregivers, and others is that research has demonstrated that persons with early-stage AD still have the ability to learn. One study showed that individuals with mild AD had a 170% improvement in ability to recall faces and names.<sup>3</sup> This suggests that AD patients who can be discharged to their homes should be encouraged to engage in mental stimulation daily.

**Clinicians and facility staff should be prepared to collaborate with community resources to get individuals with AD and their families the support, assistance, and guidance they need.**

### Err on the Side of the Resident

If physicians and family members are quick to place people with AD in nursing homes, it likely is because these individuals are concerned about patients' safety and long-term health. However, there are times when it is acceptable and appropriate to release residents back into the community.

Comprehensive discharge planning that includes coordination with residents, family, physician, and other health care providers; access to support agencies; and rigorous education can enhance the possibility for these people to remain in their own homes or assisted living dwellings. This planning also can help both residents and their family members overcome their immediate feelings of hopelessness associated with this disease. In fact, deliberate discharge planning may be the most important intervention in terms of securing the best quality of care and quality of life as patients learn to live with their diagnosis.

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