

COMMENTS OF CONSTANT CARE FAMILY MANAGEMENT SUBMITTED TO HSS ON THE

DRAFT Framework for the National Plan to Address Alzheimer's Disease

MARCH 5, 2012

We are excited about the opportunity to offer our comments and recommendations regarding the *Draft Framework for the National Plan to Address Alzheimer's Disease*.

As memory care experts, our Autumn Leaves assisted living communities provide families and residents with compassionate care and innovative solutions that help our residents create a sense of well-being in a comfortable, home-like environment. While reviewing the Draft Framework, we agree with our industry partner, The Assisted Living Federation of America (ALFA) that the framework is a good start but there are more components that need to be added to the story.

The recommendations below offer ideas, interpretations and new measures in the draft where we think the strategy can be better fortified to help industry professionals, and residents and their families make more informed decisions while promoting the need to educate, train, detect and respond faster to this deadly disease. Thank you for the opportunity to hear our voice.

Strategy 2.B: Ensure Timely and Accurate Diagnosis

Training and specialized programs need mandating for general practitioners, and the healthcare industry overall to recognize early signs and symptoms. Requirements need to be established for individuals 70 years of age and older. Parameters, tools, programs and interview questions that allow physicians to screen for Alzheimer's and dementia need to be implemented much like the way breast cancer checks and prostate exams are set up.

Strategy 2D: Identify and Implement High-Quality Dementia Care Guidelines and Measures Across Care Settings

While guidelines for delivery of high-quality care and measures are needed, even more important is the focus on specialized cognitive care activities such as the way to evaluate an individual's ability to complete day to day activities. The goal should be to improve an individual's life by identifying their remaining abilities and offering recommendations and strategies.

Strategy 2.E: Ensure that People with Alzheimer's Disease Experience Safe and Effective Transitions Between Care Settings and Systems

More training and programs need to be implemented on the potential impacts of cognitively impaired individuals, and how transitions disorient and stress the individual.

Strategy 2.G: Improve Care for Populations Disproportionally Affected by Alzheimer’s Disease

Better controls and programs need to be established to understand family systems which can oftentimes present a barrier to diagnosis and treatment. Identify the cultural dynamic of communication in order to offer support, education, awareness and help. Likewise, provide support and assistance for younger families so they can have access to the latest information: where to get help, programs designed to provide that help and community outreach services to offer support.

Strategy 3.C: Assist Families in Planning for Future Long-Term Care Needs

More awareness programs and information about the importance of planning for healthcare decisions and disease progress need to be available. The primary physician and social worker roles need to be better quantified so they can better help families navigate through this process. Recognition of specific dementia care and related long-term care settings must be identified by policy makers and the insurance industry. More help is needed to assist families with guardianship and how to plan ahead, understand how to deal with crisis moments and realize they need professional legal help for healthcare issues and financial.

Strategy 3.D: Maintain the Dignity, Safety, and Rights of People with Alzheimer’s Disease

Programs, training and information need to be available to help educate families and individuals on recognizing abuse and exploitation. Consequently, safety programs, education and training need to be implemented to address issues like wandering and safe return/finding.

A series of safety programs need to be implemented to help:

- Caregivers prepare their homes for a loved one living with Alzheimer’s.

- First responders such as police, fire department, EMS and emergency room personnel understand the necessary steps to take when aiding individuals who are living with Alzheimer’s or dementia.

Strategy 4.A: Educate the Public about Alzheimer’s Disease

As the disproportionately high rate of African-Americans versus whites living with Alzheimer’s continues to rise, more educational services need to be available in the African-American communities to help increase a greater awareness and knowledge-base of the warning signs of Alzheimer’s and dementia. The Alzheimer’s Association statistics illustrate that the age-specific prevalence of dementia has been found to be 14% to 100% higher in African-American.* The number of African-American age 65 and over will more than double by 2030, from 2.7 million in 1995 to 6.9 million.

* Source:

Alzheimer’s Association: *African-Americans and Alzheimer’s Disease: The Silent Epidemic*

The Wandering Emergency

Wandering is considered an Emergency. Although common, wandering can be dangerous – even life threatening: speed is of the essence. The statistics show very poor outcomes for elderly wanderers missing beyond 24 hours, and many people cannot remember their name or address. They may become disoriented and lost even in their own neighborhood, and they may become fearful and hide. Many states do not track or report wandering and locating current, up to date statistics are difficult to obtain.

Wandering is an emergency situation and part of the disease process:

- 6 in 10 people with Alzheimer’s disease will wander.
- 18% of those with mild dementia wander.
- 50% of those with severe dementia wander.
- Wandering has proven such a common behavior that experts predict 60% to 70% of all people with Alzheimer’s will wander away from safety at least once during the course of their illness.
- Many will wander 6 to 8 times before they are placed into a residential facility or an outside, qualified caretaker is brought into the home to help.

At Autumn Leaves, we’re exploring ways to adapt our communities into designated *Safe Havens*. We know as individuals lose more and more of their memory, they will often go in search of a particular person, place or thing.

We are working to provide a service where anyone in the public sector that finds an individual wandering, confused of their whereabouts or are lost, can bring that individual to an Autumn Leaves *Safe Haven* until authorities or family members are contacted. We want to be able to help the emergency responders, and give them the aid and support they need to return individuals back to their loved ones.

Our solution to this very serious issue is multi-faceted:

- Expansion of the Silver Alert Program needs activation standards set by federal legislation to ensure there is seamless integration nationally instead of state by state much like the Amber Alert system introduced in 1996. Approximately 29 states have a Silver Alert or similar programs – all states need to implement and participate.
- Education on wandering prevention needs implementation along with understanding GPS technology or emerging technologies.
- The Safe Haven concept for ‘found’ wanderers needs regional awareness to inform the public where and how to find Safe Havens. Likewise, they will need to be informed of the steps in bringing Alzheimer’s or dementia wanderers to safe communities.

*** Source:**

Alzheimer’s Association: *Wandering: Preparing for and Preventing It 2007*

Alzheimer’s America: <http://www.alzheimersamerica.com/wandering.html>