

October 29, 2007

Iowa Alzheimer's Disease Task Force

I come before you today to express my thoughts and input on Alzheimer's disease and its impact on the nutritional status of those with this diagnosis. As a member of the American Dietetic Association, with a membership of over 70,000 members and the Iowa Dietetic Association as well as personally being a registered dietitian certified as a specialist in gerontological nutrition who has worked in CCDI units and dementia specific assisted living units, my main concern is the nutritional care provided to those with dementia and the impact this Task Force can have on providing nutritional care for those here in my home state.

As the population ages, the prevalence of cognitive impairment including Alzheimer's will become an increasing burden on the health care system. Because life expectancy has increased to nearly twice what it was a century ago, the incidence of dementia appears to be increasing. The likelihood that elderly individuals will demonstrate loss of cognitive function the longer they live becomes greater. This often translates into greater caregiver burden and then institutionalization. With Iowa's population of elderly increasing this will certainly place a stress on already tight funding dollars.

The need for screening for nutritional problems and providing appropriate nutritional care is important for people with dementia/Alzheimer's disease. Some dementias are even reversible, particularly those that are nutrition-related. If this is suspected, the first step in intervention should be a trial of replacing deficient nutrients and observing improvement in cognitive function. This is a reasonable strategy with minimal cost and is non-invasive; response to treatment either medication, nutrient supplementation or both usually occurs in a short time frame. This could easily be done in the home environment and allow the patient more quality time with family members. Dementia caused by brain pathology, however, is not reversible. Dr. Bender who is a member of this task force has completed research in the use of vitamin and mineral supplements for those with this disease.

The values of treating this population are many. Some treatment regimes may improve functioning, maintain current level of functioning, or slow decline in functioning. Maximizing nutritional health both during this maintenance phase and the declining phase can improve the quality life for the individual suffering from this diagnosis.

Research suggests the typical person with Alzheimer's disease goes through several stages that impact their nutritional health. It may start with forgetting they ate or wanting to eat all of the time followed by weight gain. Another stage is losing the ability to feed ones self; first forgetting how to use a knife, then the fork and eventually using only their fingers to eat. This is very similar to the reverse order for how we learned to eat. During this loss of self-feeding skills, many refuse assistance in the dining process and lose weight. Weight loss in older adults represents a loss of muscle more than fat. The loss of muscle means the individual will become weaker, have more difficulty walking, getting

in and out of a chair or toileting independently. Since swallowing requires the use of muscles, dysphasia may also develop as well as chewing problems. This scenario creates a significant burden on already stressed caregivers.

Nutrition management to maintain food intake and the increased calorie needs often required in this population must be a priority. Although challenging and ever changing over the course of the disease, nutrition management requires individualization according to the client's ability and current stage of disease. It is well documented that death rate is lowest when body weight as a percentage of usual body weight is maintained within 90%; serum albumen is >3.5 gm/dl; hematocrit is $>41\%$ and serum cholesterol is maintained >160 mg/dl.

The consequences of poor nutritional health include increased health costs and decreased health outcomes. Without proper nutrition this population is susceptible to a rapid decline in health, increased risk of infections, respiratory problems, skin breakdown with ulceration, poor wound healing, weakness and poor mobility, and impaired cardiac function. Many times this decline results in institutionalization of the individual increasing the use of already stretched health care dollars.

All of us here today probably feel we know best for the person with dementia—what they should eat, how they should eat, and when they should eat. Yet, even profoundly demented people can still direct their care based on their behavior. When they readily accept a certain food, they are directing us to give them that food. When they're spitting out a certain food, they may be saying "No more of that!"

However, we want to make sure that spitting out food is truly a refusal to eat rather than the caregiver not knowing techniques that will maximize meal intake. Those with dementia may demonstrate numerous symptoms that effect eating. Losses associated with dementia may include decreased or abnormal senses of taste and smell where food smells rotten or tastes burnt. Dementia patients may lose their ability to recognize food but non-food items that are visually appealing may be consumed such as flowers, plants, or brightly colored paper objects. In advanced dementia, individuals may forget that they have eaten recently; may consume non-food items; may chew and forget to swallow; may pocket food that places them at risk for choking, spit food out, or demonstrate other unusual eating behaviors. These behaviors that are associated with mealtimes illustrate the need for caregivers to have specialized training

This group of individuals may also demonstrate significant changes in body weight. Although there have been many theories about why this happens, there are presently no clear explanation or evidence-based research identifying reasons. It has been hypothesized that there is a change in metabolism associated with dementia but no one has been able to demonstrate this in a controlled environment. Some individuals may develop pacing or wandering behaviors that contribute to an increase in energy expenditure while others may become more sedentary and not require as many calories for energy.

It will be extremely important that care givers, family members, volunteers and long term care staff understand all of these changes and thus the importance of nutrition. This group must be provided with a nutrition/dining assistance component that explains to them what techniques might work for the various behaviors. The Consultant Dietitians in Health Care Facilities, a practice group of the American Dietetic Association has already developed a manual that could be used for this training. "Dining Skills: Practical Interventions for the Caregivers of Older Adults with Eating Problems" provides training techniques including how to approach a person with dementia. These approaches can be used for both assisting with meals or with oral cares. This is important for this group since poor oral care affects the taste of food, increases dental problems which can lead to dental pain which in turn contributes to increases in behaviors at mealtimes.

Nutritional status may also be impacted by medications. Medications may cause loss of appetite while others may cause an increase in appetite. Some drugs may contribute to adverse gastrointestinal side effects. It is difficult to categorize changes that occur with dementias without recognition that each individual may have a unique symptomatology and must be treated differently. The registered dietitian is trained in examining medications that may impact this population's overall nutrition intake, again with the potential of reducing overall costs.

Eating behavior may be sporadic, unpredictable and unusual in those with dementia. Several studies have demonstrated that it is best to have meals associated with a low stress environment where noise and visual stimulation is kept to a minimum. A quiet, well-lit room without too many people around will minimize mealtime stress and distraction. Developing a routine that can be sustained over time will be a first step to successful meals. Many who are diagnosed with dementia have a very short attention span; although it is time consuming and labor intensive, having one person spend the entire mealtime with an uninterrupted feeding schedule may contribute to an increase in food consumption in those whose attention drifts easily. Even developing a routine meal pattern with similar and familiar foods every day may serve as a cue for those with dementia to eat. This becomes a challenge for nursing facilities to provide an individual's routine. Sometimes family members are more successful in getting their loved one to eat than nursing facility staff; this may be associated with a sense of familiarity with the family member and the undivided attention provided in this situation.

When those with dementia demonstrate behaviors such as repetitive chewing, pocketing foods, an unwillingness to allow someone to assist them with meal intake, there are skills that can be learned by caregivers to overcome some of these behaviors. The American Dietetic Association in their position paper, "Liberalization of the Diet Prescription Improves Quality of Life for Older Adults in Long-Term Care" states: "Dementia syndromes may impair self-feeding, alter appetite and increase energy needs. Nutrition restriction may make food less appetizing, resulting in diminished intake and weight loss. Overly restrictive diets, such as those low in cholesterol/fat, salt, and sugar, may take much of the enjoyment out of eating...The use of a more liberalized approach produces several benefits, including better intake, lower incidence of unintended weight loss, more consistent blood glucose levels, and, perhaps most important quality of life." The

expertise of a registered dietitian is needed to ensure the most appropriate diet and mealtime interventions are being used. Then training must be provided to care givers; both those providing care in the home and those in the long-term care facilities that include such mealtime strategies.

One such strategy for individuals with memory loss who may not recall having eaten and may look for additional food between meal is to divide meals into small portions to create 6 or 8 smaller meals. This helps the person with dementia to have a sense of control over his or her environment as well as prevent an unintended weight gain. A similar strategy of providing snacks or small meals between regularly scheduled mealtimes may also contribute to maintaining weight in agitated patients or those who demonstrate pacing or wandering behaviors.

The registered dietitian is trained in identifying many of these symptoms and is well educated in the clinical observations that may occur with malnutrition and dehydration as well as the loss of texture tolerance most generally seen in those with Alzheimer's. Nutrition management should include appreciation for individualization in defining needs; nutrition assessment; nutrition intervention; and ongoing monitoring. It is important for the registered dietitian to be aware when an unusual event occurs to the person with dementia. Significant weight change, fevers, infection, injuries, influenza and other illnesses may impact on the need for energy, protein, and fluid in excess of calculated dietary goals. The issue is to meet increased nutrient requirements in times of physiological stress.

During my 30+ years as a registered dietitian working with this population and as the current Director of Clinical Nutrition and Dining Services at Western Home Communities in Cedar Falls where I have nutrition responsibility for our 32 unit assisted living dementia unit, I have identified approaches that have been successful in this population. Serving larger meals at breakfast and dinner have most often worked for the majority of this population with smaller intake at supper due to "sundowning." Providing nutrient-dense familiar foods—super pudding, super oatmeal, super mashed potatoes and other comfort foods with additional corn syrup, flavored syrups, honey, half and half and margarines are ideas and recipes that the registered dietitians can provide to families, care givers and staff. Increasing fluids with the use of popsicles, beverages next to their favorite chair and adding lemon or lime to water are often suggestion made by the registered dietitian.

Nutrition approaches may also be successful in calming those with dementia. Research has suggested that food rich in carbohydrates or B6 may have a calming effect on brain chemistry. Minimizing mealtime confusion, discontinuing foods not easily kept on a spoon, peeling fruit prior to providing to the person, offering finger foods, providing soup in a mug and using spaghetti bowls or high sided plates in place of a routine dinner plate are all viable solutions for those with dementia. Serving dinner rolls in place of white bread that they may consider a napkin, providing only the utensils needed, avoiding plastic flatware that may break, and demonstrating the action of eating and drinking have

also been found to be successful and are well known approaches used by the registered dietitian working with this population.

Providing adequate nutrition and appropriate feeding for those with Alzheimer's is a challenge. Assessing the person's eating skills, including chewing and swallowing, interest in food, attention span, resources to support help with dining, potential need for nutrition support, and prognosis, is essential to develop a quality plan of care for maintaining or improving nutritional status that is so very important in this population.

I ask, that as you develop your recommendations that you include nutritional care in the services provided to this population by:

- 1. Making provisions so that a registered dietitian is involved with nutrition screening, nutrition assessment, developing an individualized plan of care to maximize nutritional health and providing education for caregivers.**
- 2. Developing caregiver training that includes nutrition and mealtime strategies to meet the needs of individuals with Alzheimer's disease.**

These two interventions are essential in maintaining individuals with Alzheimer's disease at the highest practicable level of functioning and quality of life.

Thank you for this opportunity to present this very valuable and important information and to represent not only Western Home Communities but also the 70,000 registered dietitians, many of whom work with this population.

Sincerely,

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