



New Dining Practice Standards

*Pioneer Network
Food and Dining Clinical Standards
Task Force*



A Rothschild Regulatory Task Force



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Introduction

Food and dining requirements are core components of quality of life and quality of care in nursing homes. Research also shows that:

50%-70% of residents leave 25% or more of their food uneaten at most meals and both chart documentation of percent eaten and the MDS are notoriously inaccurate, consistently representing a gross under-estimate of low intake.^{1, 2}

60%-80% of residents have a physician or dietitian order to receive dietary supplements.³

25% of residents experienced weight loss when research staff conducted standardized weighing procedures over time.^{4, 5}

The American Dietetic Association (ADA) reports that under-nutrition adversely affects the quality and length of life, and therefore, has aroused the concern of geriatric health professionals. The prevalence of protein energy under-nutrition for residents ranges from 23% to 85%, making malnutrition one of the most serious problems facing health professionals in long term care. Malnutrition is associated with poor outcomes and is an indicator of risk for increased mortality. It has been found that most residents with evidence of malnutrition were on restricted diets that might discourage nutrient intake.⁶

CMS notes that the most frequent questions and concerns received by their staff focus on the physical environment and dining/food policies in nursing homes. Therefore, in 2010 the Pioneer Network and CMS held their second co-sponsored national symposium Creating Home II National Symposium on Culture Change and the Food and Dining Requirements, sponsored by the Hulda B. & Maurice L. Rothschild Foundation. The Symposium brought together a wide diversity of stakeholders, including nursing home staff, regulators, provider leadership, researchers, registered dietitians, vendors, and advocates for culture change.

¹ Simmons SF & Reuben D. (2000). Nutritional intake monitoring for nursing home residents: A comparison of staff documentation, direct observation, and photography methods. Journal of the American Geriatrics Society, 48(2):209-213.

² Simmons SF, Lim B & Schnelle JF. (2002). Accuracy of Minimum Data Set in identifying residents at risk for undernutrition: Oral intake and food complaints. Journal of the American Medical Directors' Association, 3(May/June):140-145.

³ Simmons SF & Patel AV. (2006). Nursing home staff delivery of oral liquid nutritional supplements to residents at risk for unintentional weight loss. Journal of the American Geriatrics Society, 54(9):1372-1376.

⁴ Simmons SF, Garcia ET, Cadogan MP, Al-Samarrai NR, Levy-Storms LF, Osterweil D & Schnelle JF. (2003). The Minimum Data Set weight loss quality indicator: Does it reflect differences in care processes related to weight loss? Journal of the American Geriatrics Society 51(10):1410-1418.

⁵ Simmons SF, Peterson E & You C. (2009). The accuracy of monthly weight assessments in nursing homes: Implications for the identification of weight loss. Journal of Nutrition, Health & Aging, 13(3):284-288.

⁶ ADA Position Paper Liberalization of the Diet Prescription Improves Quality of Life for Older Adults in Long-Term Care 2005.

The Pioneer Network is a growing coalition of organizations and individuals from across the nation, changing the culture of aging and long term care. Pioneer Network is dedicated to making fundamental changes in values and practices to create a culture of aging that is life-affirming, satisfying, humane and meaningful. It advocates for public policy change, creates communication, networking and learning opportunities; builds and supports relationships and community; identifies and promotes transformation in practice, services, public policy and research; develops and provides access to resources and leadership; and hosts a national conference to bring together interested parties with a desire to propel this important work.

The Hulda B. & Maurice L. Rothschild Foundation is the only national philanthropy exclusively focused on improving the quality of life for elders in nursing homes throughout the United States. One of its key strategies is to work together with significant stakeholders in order to modify existing regulations, such that they better support new models of aging in long term care. Currently, the Foundation has initiated and is supporting a number of such efforts:

- The National Life Safety Task Force convened by Pioneer Network that has revisions pending to the National Life Safety Code.
- The Center for Health Design expert panel that is developing recommendations for the guidelines which govern the Design and Construction of Healthcare Facilities.
- The American Institute of Architects Design for Aging Community that is drafting a Proposal for Changes to Accessibility Standards for Nursing Home & Assisted Living Residents in Toileting and Bathing under the Americans with Disabilities Act.
- At the specific request of the regulatory community, the Foundation has supported the University of Minnesota in building a free website, NHRegsPlus, which provides a cross - indexed compendium of all state nursing home regulations.

Food and dining are an integral part of individualized care and self-directed living for several reasons, including: (1) the complexity of food and dining requirements when advancing models of culture change; (2) the importance of food and dining as a significant element of daily living, and (3) the most frequent questions and concerns CMS receives from regulators and providers consistently focus on dining and food policies in nursing homes. Therefore, we believe this area is one most in need of national dialogue if we are to improve quality of life for persons living in nursing homes while maintaining safety and quality of care.

In order to gather input from the many key stakeholders, the Creating Home II National Symposium on the Food and Dining Requirements and Culture Change was co-sponsored by Pioneer Network and CMS, in collaboration with the American Health Care Association. A set of research papers were commissioned with a wide variety of experts as well as a

series of webinars, hosted by Carmen Bowman under contract with CMS, and all were posted online. This process allowed many members of interested organizations, associations, regulatory departments, and others to participate. The Hulda B. & Maurice L. Rothschild Foundation supported a Stakeholder Workshop on May 14, 2010 that was attended by 83 national leaders, which reviewed the feedback from all stakeholders, expert speakers and individual participants. Two of the numerous recommendations at the Creating Home II symposium for future consideration were:

National stakeholder workgroup develop guidelines for clinical best practice for individualization in long term care living to provide regulatory overview and interpretive protocol and investigative guidance, and prepare related education materials to facilitate implementation.

Each profession serving elders in long-term care develop and disseminate standards of practice for their professional accountability that addresses proper training, competency assessment, and their role as an active advocate for resident rights and resident quality of life from a wellness perspective in addition to quality of care from a medical perspective.

These recommendations were acted upon at least in part thanks to the generous funding of the Hulda B. and Maurice L. Rothschild Foundation to the Pioneer Network in 2011 by forming the Food and Dining Clinical Standards Task Force. The Food and Dining Clinical Standards Task Force is comprised of symposium experts, representatives from Centers for Medicare and Medicaid Services Division of Nursing Homes, the US Food and Drug Administration and the Centers for Disease Control and Prevention as well as national standard setting groups.

The Food and Dining Clinical Standards Task Force made a significant effort to obtain evidence and thus the New Dining Practice Standards document reflects evidence-based research available to-date. The document also reflects current thinking and consensus which are in advance of research. Therefore the Current Thinking portions of each section of the New Dining Practice Standards document represent a list of recommended future research.

GOAL STATEMENT: Establish nationally agreed upon new standards of practice supporting individualized care and self-directed living versus traditional diagnosis-focused treatment.

Organizations Agreeing to the New Dining Practice Standards

- American Association for Long Term Care Nursing (AALTCN)
- American Association of Nurse Assessment Coordination (AANAC)
- American Dietetic Association (ADA)
- American Medical Directors Association (AMDA)
- American Occupational Therapy Association (AOTA)
- American Society of Consultant Pharmacists (ASCP)
- American Speech-Language-Hearing Association (ASHA)
- Dietary Managers Association (DMA)
- Gerontological Advanced Practice Nurses Association (GAPNA)
- Hartford Institute for Geriatric Nursing (HIGN)
- National Association of Directors of Nursing Administration in Long Term Care (NADONA/LTC)
- National Gerontological Nursing Association (NGNA)

Note to reader:

Regular diet is referred to often in this document. Regular diet is defined as what should be prepared and offered to meet nutritional needs in accordance with the current recommended dietary allowances of the Food and Nutrition Board of the National Research Council, National Academy of Sciences, used as a standard meal planning guide while residents have the right to make choices.

Whenever physician is referred to in this document, it is recognized that medical care may be delivered by a physician, or a nurse practitioner, or a physician assistant under the direction of a physician in accordance with state licensure law.

Borrowing from CMS interpretive guidance and probe language at Tag F280 and Tag F281:

Tag F280:

“Interdisciplinary” means that professional disciplines, as appropriate, will work together to provide the greatest benefit to the resident.

The physician must participate as part of the interdisciplinary team, and may arrange with the facility alternate methods other than attendance at care planning conferences, of providing his/her input, such as one-on-one discussions and conference calls.

Some interdisciplinary professional disciplines include the occupational therapist, dietitian and speech therapist as the Probes at Tag F280 indicate:

Was interdisciplinary expertise utilized to develop a plan to improve the resident’s functional abilities?

- a. For example, did an occupational therapist design needed adaptive equipment or a speech therapist provide techniques to improve swallowing ability?

- b. Do the dietitian and speech therapist determine, for example, the optimum textures and consistency for the resident's food that provide both a nutritionally adequate diet and effectively use oropharyngeal capabilities of the resident?
- c. Is there evidence of physician involvement in development of the care plan (e.g., presence at care plan meetings, conversations with team members concerning the care plan, conference calls)?

Tag F281:

“Professional standards of quality” means services that are provided according to accepted standards of clinical practice. Standards may apply to care provided by a particular clinical discipline or in a specific clinical situation or setting. Standards regarding quality care practices may be published by a professional organization, licensing board, accreditation body or other regulatory agency. Recommended practices to achieve desired resident outcomes may also be found in clinical literature. Possible reference sources for standards of practice include:

- Current manuals or textbooks on nursing, social work, physical therapy, etc.
- Standards published by professional organizations such as the American Dietetic Association, American Medical Association, American Medical Directors Association, American Nurses Association, National Association of Activity Professionals, National Association of Social Work, etc.
- Clinical practice guidelines published by the Agency of Health Care Policy and Research.
- Current professional journal articles.

Similarly, whenever “interdisciplinary team” is referred to in this document, it can and is recommended that it include extended technical, support, and administrative team members such as Certified Nursing Assistants, (CNAs), Patient Care Technicians (PCTs), directors of food service (including Certified Dietary Managers (CDMs) & Dietetic Technicians, Registered (DTRs), cooks, housekeepers, and cross trained/blended workers.

This document comprises numerous quotations from many professional organizations, thus a variety of nomenclature is used. There has been no effort to edit or standardize the nomenclature referring to people who live in long term care settings, e.g. elders, residents, clients, patients or to describe where they live, e.g. facilities, nursing homes, homes and communities.

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Standard of Practice for Individualized Nutrition Approaches/Diet Liberalization

Basis in Current Thinking and Research

American Medical Directors Association (AMDA):

Weight loss is common in the nursing home and associated with poor clinical outcomes such as the development of pressure ulcers, increased risk of infection, functional decline, cognitive decline and increased risk of death. One of the frequent causes of weight loss in the long-term care setting is therapeutic diets. Therapeutic diets are often unpalatable and poorly tolerated by older persons and may lead to weight loss. The use of therapeutic diets, including low-salt, low-fat, and sugar-restricted diets, should be minimized in the LTC setting.⁷

Attending physicians are encouraged to consider liberalizing dietary restrictions (e.g., calorie limitation, salt restrictions) that are not essential to the resident's well being, and that may impair quality of life or acceptance of diet.⁸

Patients and families who have become accustomed to dietary restrictions while at home or in the acute care setting may need to be educated about this change in thinking. Swallowing abnormalities are common but do not necessarily require modified diet and fluid textures, especially if these restrictions adversely affect food and fluid intake.⁹

American Dietetic Association (ADA):

It is the position of the American Dietetic Association that the quality of life and nutritional status of older residents in long-term care facilities may be enhanced by liberalization of the diet prescription. Medical nutrition therapy must balance medical needs and individual desires and maintain quality of life. The recent paradigm shift from restrictive institutions to vibrant communities for older adults requires dietetics professionals to be open-minded when assessing risks versus benefits of therapeutic diets, especially for frail older adults. Food is an essential component of quality of life; an unacceptable or unpalatable diet can lead to poor food and fluid intake, resulting in weight loss and undernutrition and a spiral of negative health effects.¹⁰

Although limited evidence supporting a medicalized diet in select older adults does exist, it is also important to note that these diets are often less palatable and poorly tolerated and can lead to weight loss. Weight loss is a far greater concern to the often frail nursing home

⁷ American Medical Directors Association Clinical Practice Guideline: Altered Nutritional Status. 2009.

⁸ AMDA Synopsis of Federal Regulations in the Nursing Home: Implication for Attending Physicians and Medical Directors 2009.

⁹ AMDA Clinical Practice Guideline: Diabetes Management in the Long-Term Care Setting 2008.

¹⁰ ADA Position Paper Liberalization of the Diet Prescription Improves Quality of Life for Older Adults in Long-Term Care 2005.

resident and easily outweighs the potential modest benefits a medicalized diet can only sometimes offer.¹¹

It is the position of the American Dietetic Association that the quality of life and nutritional status of older adults residing in health care communities can be enhanced by individualization to less-restrictive diets. Although therapeutic diets are designed to improve health, they can negatively affect the variety and flavor of the food offered. Individuals may find restrictive diets unpalatable, resulting in reducing the pleasure of eating, decreased food intake, unintended weight loss, and undernutrition – the very maladies health care practitioners are trying to prevent. In contrast, more liberal diets are associated with increased food and beverage intake. For many older adults residing in health care communities, the benefits of less-restrictive diets outweigh the risks.¹²

Centers for Medicare and Medicaid Services (CMS):

Liberalized diets should be the norm, restricted diets should be the exception. Generally weight stabilization and adequate nutrition are promoted by serving residents regular or minimally restricted diets.¹³

Research suggests that a liberalized diet can enhance the quality of life and nutritional status of older adults in long-term care facilities. Thus, it is often beneficial to minimize restrictions, consistent with a resident's condition, prognosis, and choices before using supplementation. It may also be helpful to provide the residents their food preferences, before using supplementation. This pertains to newly developed meal plans as well as to the review of existing diets. Dietary restrictions, therapeutic (e.g., low fat or sodium restricted) diets, and mechanically altered diets may help in select situations. At other times, they may impair adequate nutrition and lead to further decline in nutritional status, especially in already undernourished or at-risk individuals. When a resident is not eating well or is losing weight, the interdisciplinary team may temporarily abate dietary restrictions and liberalize the diet to improve the resident's food intake to try to stabilize their weight. Sometimes, a resident or resident's representative decides to decline medically relevant dietary restrictions. In such circumstances, the resident, facility and practitioner collaborate to identify pertinent alternatives (CMS Tag F 325 Nutrition).¹⁴

Current Thinking

Given that most nursing home residents are at risk for malnutrition and may in fact have different, therapeutic targets for blood pressure, blood sugar and cholesterol, a regular or liberalized diet which allows for resident choice is most often the preferred initial choice.

¹¹ Gardner CD, Coulston A, Chatterjee L, Rigby A, Spiller G, Farquhar JW, The effect of a plant-based diet on plasma lipids in hypercholesterolemic adults: a randomized trial. *Intern Med.* 2005;142 (9):725.

¹² ADA Liberalization of the Diet Prescription Improves Quality of Life for Older Adults in Long-Term Care 2005.

¹³ CMS Satellite Broadcast From Institutional to Individualized Care: Case Studies in Culture Change, Part III, 2007 available from the Pioneer Network www.pioneernetwork.net.

¹⁴ State Operations Manual for LTC Facilities, Appendix PP, 483.25(i) F 325 Nutrition, 2008 Guidance.

As with any medical issue, residents should be monitored for desired outcomes as well as for potential adverse effects.¹⁵

Some homes have actually made the “regular” diet with ranges of consistency modifications such as "puree to mechanical soft" their only available option, then honored the resident's choice to eliminate "not recommended" foods from his/her diet by choice, then monitored his/her clinical outcomes and made changes as necessary. That being said, homes with transitional care units or that serve younger disabled people may choose to offer the more restrictive diets as an option for long term health.¹⁶

All persons moving into a nursing home receive a regular diet unless there is a strong medical historical reason to initiate/continue a restricted diet. Those who require medicalized diets can be assessed by the dietitian, physician, and if necessary the speech therapist for appropriate individualized modification. There needs to be continuous monitoring of the usage of all medicalized diets to ensure that they continue to be medically indicated, much the same way the usage of urinary catheters or other medical devices are monitored. When potential interventions have the ability to both help and harm, such as medicalized diets and thickened liquids, the interventions should be reviewed by the interdisciplinary team in a holistic fashion and discussed with the resident and/or their family/POA prior to their implementation. Residents and/or their families/POA should be educated regarding these interventions and the care plan monitored for both safety and effectiveness. The physician and interdisciplinary team should treat asymptomatic disease PROVIDED it is consistent with the resident's goals for care, is SUPPORTED by the literature and DOES NOT DECREASE QUALITY OF LIFE.¹⁷

Relevant Research Trends

See below for relevant research to each specific diet.

¹⁵ Leible and Wayne, The Role of the Physician's Order, paper written for CHII 2010.

¹⁶ Bump, Linda. Clinical Standards Task Force communication, 2011.

¹⁷ Leible and Wayne, The Role of the Physician's Order, paper written for CHII 2010.

Recommended Course of Practice

- Diet is to be determined with the person and in accordance with his/her informed choices, goals and preferences, rather than exclusively by diagnosis.
- Assess the condition of the person. Include quality of life markers such as satisfaction with food, meal time service, level of control and independence.
- Assess the condition of the person. Assess and provide the person's preferred context and environment for meals, in other words the person's preferences, patterns and routines for socialization (i.e. eating alone or with others), physical support (i.e. adapted eating utensils, assistance with cartons/cutting or adapted w/c positioning), timing of meals (i.e. typical community or unique meal times) and personal meaning/value of the dining experience (i.e. for one who does not eat breakfast, breakfast is not important but perhaps an early lunch is). Include quality of life markers such as satisfaction with food, service received during meals, level of control and independence.
- Unless a medical condition warrants a restricted diet, consider beginning with a regular diet and monitoring how the person does eating it.
- Empower and honor the person first, and the whole interdisciplinary team second, to look at concerns and create effective solutions.
- Support self-direction and individualize the plan of care.
- Ensure that the physician and consultant pharmacist are aware of resident food and dining preferences so that medication issues can be addressed and coordinated i.e. medication timing and impact on appetite.
- Monitor the person and his/her condition related to their goals regarding nutritional status and their physical, mental and psychosocial well-being.
- Although a person may have not been able to make decisions about certain aspects of their life, that does not mean they cannot make choices in dining.
- When a person makes “risky” decisions, the plan of care will be adjusted to honor informed choice and provide supports available to mitigate the risks.
- Most professional codes of ethics require the professional to support the person/client in making their own decisions, being an active, not passive, participant in their care.
- When caring for frail elders there is often no clear right answer. Possible interventions often have the potential to both help and harm the elder. This is why the physician must explain the risks and benefits to both the resident and interdisciplinary team. The information should be discussed amongst the team and resident/family. The resident then has the right to make his/her informed choice even if it is not to follow recommended medical advice and the team supports the person and his/her decision, mitigating risks by offering support, i.e. offering foods of natural pureed consistency when one refuses recommended tube feeding. It is when the team makes decisions for the person without acknowledgement by all that problems arise. The agreed upon plan of care should then be monitored to make sure the community is best meeting the resident's needs.
- All decisions default to the person.

Standard of Practice for Individualized Diabetic/Calorie Controlled Diet

Basis in Current Thinking and Research

AMDA:

“...intensive treatment of diabetes may not be appropriate for all individuals in the LTC setting. To improve quality of life, diagnostic and therapeutic decisions should take into account the patient’s cognitive and functional status, severity of disease, expressed preferences, and life expectancy.”¹⁸

An individualized regular diet that is well balanced and contains a variety of foods and a consistent amount of carbohydrates has been shown to be more effective than the typical treatment of diabetes.¹⁹

ADA:

There is no evidence to support prescribing diets such as no concentrated sweets or no sugar added for older adults in living in health care communities, and these restricted diets are no longer considered appropriate. Most experts agree that using medication rather than dietary changes to control blood glucose, blood lipid levels, and blood pressure can enhance the joy of eating and reduce the risk of malnutrition in older adults in health care communities.²⁰

CMS:

Nothing specific to diabetes was found, however, CMS has stated much about liberalizing diets, see Diet Liberalization section as well as each specific diet section.

Current Thinking

If a person with diabetes chooses not to eat breakfast, for example, that decision should be made and communicated before a dose of regular insulin is administered in the morning. While we agree that people should be given as much freedom as possible in choice of diets and foods, it may be more appropriate in many cases to liberalize the treatment goals or targets (such as hemoglobin A1C or cholesterol) rather than add more medication.²¹

The only benefit to sliding scale insulin is with a new diagnosis where the clinician is attempting to estimate daily dosage of insulin. For this reason, insulin sliding scale should be used sparingly if at all, and glucose monitoring should be done no more than once daily in stable diabetics, more frequently, albeit temporary, if actively adjusting the regimen.²²

¹⁸ AMDA Clinical Practice Guidelines: Diabetes Management in the Long-Term Care Setting 2008.

¹⁹ AMDA Clinical Practice Guideline: Diabetes Management in the Long-Term Care Setting 2008.

²⁰ ADA Position Paper Individualized Nutrition Approaches for Older Adults in Health Care Communities 2010.

²¹ Food and Dining Clinical Standards response, 3/23/11 American Society of Consultant Pharmacists.

²² Leible and Wayne, The Role of the Physician’s Order, paper written for CHII 2010.

More than once daily blood sugars in stable diabetic patients should be discouraged (Ibid).

Elderly nursing home residents with diabetes can receive a regular diet that is consistent in the amount and timing of carbohydrates, along with proper medication to control blood glucose levels (Ibid).

Relevant Research Trends

The traditional treatment of diabetes of a “no concentrated sweets” and a liberal diabetic diet have not been shown to improve glycemic control in nursing home residents.²³

Recent studies have failed to show that tight glycemic control prevents heart attacks and strokes in diabetics and may in fact worsen outcome.²⁴ Tighter glycemic control may prevent long term complications of diabetes such as retinopathy, neuropathy and nephropathy in newly diagnosed diabetics however these conditions take years to develop and few, if any, older adults would benefit from this approach.²⁵

Given the lack of clear evidence to guide treatment in the older adult population, AMDA recommends individualizing the treatment plan based on a resident’s underlying medical condition and associated co-morbidities and has stated a target hemoglobin A1C between 7 and 8 is reasonable.²⁶

Little evidence supports the use of sliding scale insulin as it is reactive in nature and fails to meet the physiologic needs of the person (Ibid).

Recommended Course of Practice

- Diet is to be determined with the person and in accordance with his/her informed choices, goals and preferences, rather than exclusively by diagnosis.
- Assess the condition of the person. Assess and provide the person's preferred context and environment for meals, in other words the person's preferences, patterns and routines for socialization (i.e. eating alone or with others), physical support (i.e. adapted eating utensils, assistance with cartons/cutting or adapted w/c positioning), timing of meals (i.e. typical community or unique meal times) and personal meaning/value of the dining experience (i.e. for one who does not eat breakfast, breakfast is not important but perhaps an early lunch is). Include quality of life markers such as satisfaction with food, service received during meals, level of control and independence.

²³ Tariq SH, Karcic E, Thomas DR, et al. The use of no-concentrated sweets diet in the management of type 2 diabetes in nursing homes. J Am Dietetic Assoc 2001; 101(12):1463-1466.

²⁴ Tariq SH, Karcic E, Thomas DR, et al. The use of no-concentrated sweets diet in the management of type 2 diabetes in nursing homes. J Am Dietetic Assoc 2001; 101(12):1463-1466

²⁵ Effects of intensive glucose lowering in type 2 diabetes. N Engl J Med 2008; 358(24):2545-255

²⁶ AMDA Clinical Practice Guideline: Diabetes Management in the Long-Term Care Setting 2008.

- Unless a medical condition warrants a restricted diet, consider beginning with a regular diet and monitoring how the person does eating it.
- Empower and honor the person first, and the whole interdisciplinary team second, to look at concerns and create effective solutions.
- Support self-direction and individualize the plan of care.
- Ensure that the physician and consultant pharmacist are aware of resident food and dining preferences so that medication issues can be addressed and coordinated i.e. medication timing and impact on appetite.
- Monitor the person and his/her condition related to their goals regarding nutritional status and their physical, mental and psychosocial well-being.
- Although a person may not be able to make decisions about certain aspects of their life, that does not mean they cannot make choices in dining.
- When a person makes “risky” decisions, the plan of care will be adjusted to honor informed choice and provide supports available to mitigate the risks.
- Most professional codes of ethics require the professional to support the person/client in making their own decisions, being an active, not passive, participant in their care.
- When caring for frail elders there is often no clear right answer. Possible interventions often have the potential to both help and harm the elder. This is why the physician must explain the risks and benefits to both the resident and interdisciplinary team. The information should be discussed amongst the team and resident/family. The resident then has the right to make his/her informed choice even if it is not to follow recommended medical advice and the team supports the person and his/her decision, mitigating risks by offering support, i.e. offering foods of natural pureed consistency when one refuses recommended tube feeding. It is when the team makes decisions for the person without acknowledgement by all that problems arise. The agreed upon plan of care should then be monitored to make sure the community is best meeting the resident's needs.
- All decisions default to the person.

Standard of Practice for Individualized Low Sodium Diet

Basis in Current Thinking and Research

AMDA:

Such dietary restrictions may benefit some individuals, but more lenient blood pressure and blood sugar goals in the frail elderly may be desirable while a less palatable restricted diet may lead to weight loss and its associated complications.²⁷

ADA:

The relationship between congestive heart failure, blood pressure, and sodium intake in the elderly population has not been well studied. The American Heart Association recommends that older adults attempt to control blood pressure through diet and lifestyle changes and recommends a sodium intake of 2 to 3 g/day for patients with congestive heart failure. However, a randomized trial of adults aged 55 to 83 years found that a normal-sodium diet improved congestive heart failure outcomes. A liberal approach to sodium in diets may be needed to maintain adequate nutritional status, especially in frail older adults.²⁸

CMS:

Dietary restrictions, therapeutic (e.g., low fat or sodium restricted) diets, and mechanically altered diets may help in select situations. At other times, they may impair adequate nutrition and lead to further decline in nutritional status, especially in already undernourished or at-risk individuals. When a resident is not eating well or is losing weight, the interdisciplinary team may temporarily abate dietary restrictions and liberalize the diet to improve the resident's food intake to try to stabilize their weight.²⁹

Relevant Research Trends

The typical two gram sodium diet that is often recommended for individuals with hypertension, has been shown to reduce systolic blood pressures, on average, by only 5 mmHg, and diastolic blood pressures by only 2.5 mmHg making this diet's effect on blood pressure modest at best and has not actually been shown to improve cardiovascular outcomes in the nursing home resident³⁰.

Guidelines for blood pressure targets for older adults differ from those for younger people. For older adults, current literature supports intervention, with medication and/or diet, only for systolic blood pressures over 160 mmHg and targets a systolic blood pressure of less than 150mmHg.³¹

²⁷ AMDA The Role of the Medical Director in Person-Directed Care White Paper, Mar. 2010, 3.

²⁸ ADA Liberalization of the Diet Prescription Improves Quality of Life for Older Adults in LTC 2005.

²⁹ CMS State Operations Manual Appendix P, Tag 325 Nutrition

³⁰ Dickinson, HO, Mason, JM, Nicolson, DJ, et al. Lifestyle interventions to reduce raised blood pressure: a systematic review of randomized controlled trials. *J Hypertens* 2006; 24:215.

³¹ Beckett, NS, Peters, R, Fletcher, AE, et al. Treatment of hypertension in patients 80 years of age or older. *N Engl J Med* 2008; 358:1887.

Lowering systolic blood pressures below 120 to 130mmHg and diastolic pressures below 65mmHg may increase mortality in the elderly.³²

Limiting salt intake in individuals with congestive heart failure is felt to be of benefit by limiting fluid retention, but the clinical experience of two medical directors of numerous nursing homes shows that this is necessary in only a minority of nursing home patients, usually those who are salt sensitive and often have advanced disease.³³

Older people have the same taste preferences as they have had all of their life, and thus low sodium, low fat meals are not always as appetizing as the normal version of a food with naturally high fat and sodium content.³⁴

Recommended Course of Practice

Low sodium diets are not shown to be effective in the long term care population of elders for reducing blood pressure or exacerbations of CHF and therefore should only be used when benefit to the individual resident has been documented.

Recommended Course of Practice

- Diet is to be determined with the person and in accordance with his/her informed choices, goals and preferences, rather than exclusively by diagnosis.
- Assess the condition of the person. Assess and provide the person's preferred context and environment for meals, in other words the person's preferences, patterns and routines for socialization (i.e. eating alone or with others), physical support (i.e. adapted eating utensils, assistance with cartons/cutting or adapted w/c positioning), timing of meals (i.e. typical community or unique meal times) and personal meaning/value of the dining experience (i.e. for one who does not eat breakfast, breakfast is not important but perhaps an early lunch is). Include quality of life markers such as satisfaction with food, service received during meals, level of control and independence.
- Unless a medical condition warrants a restricted diet, consider beginning with a regular diet and monitoring how the person does eating it.
- Empower and honor the person first, and the whole interdisciplinary team second, to look at concerns and create effective solutions.
- Support self-direction and individualize the plan of care.
- Ensure that the physician and consultant pharmacist are aware of resident food and dining preferences so that medication issues can be addressed and coordinated i.e. medication timing and impact on appetite.

³² Oates DJ, Berlowitz DR, Glickman ME, Silliman RA, Borzecki AM. Blood pressure and survival in the oldest old. *J Am Geriatr Soc* 2007; 55(3):383-8.

³³ Leible and Wayne, The Role of the Physician Order, paper written for CHII 2010.

³⁴ Calverley, D. "The Food Fighters." *Nursing Standard*, Vol. 22, 2007, 20-21.

- Monitor the person and his/her condition related to their goals regarding nutritional status and their physical, mental and psychosocial well-being.
- Although a person may have not be able to make decisions about certain aspects of their life, that does not mean they cannot make choices in dining.
- When a person makes “risky” decisions, the plan of care will be adjusted to honor informed choice and provide supports available to mitigate the risks.
- Most professional codes of ethics require the professional to support the person/client in making their own decisions, being an active, not passive, participant in their care.
- When caring for frail elders there is often no clear right answer. Possible interventions often have the potential to both help and harm the elder. This is why the physician must explain the risks and benefits to both the resident and interdisciplinary team. The information should be discussed amongst the team and resident/family. The resident then has the right to make his/her informed choice even if it is not to follow recommended medical advice and the team supports the person and his/her decision, mitigating risks by offering support, i.e. offering foods of natural pureed consistency when one refuses recommended tube feeding. It is when the team makes decisions for the person without acknowledgement by all that problems arise. The agreed upon plan of care should then be monitored to make sure the community is best meeting the resident's needs.
- All decisions default to the person.

Standard of Practice for Individualized Cardiac Diet

Basis in Current Thinking and Research

AMDA:

Routine dietary restrictions are usually unnecessary and can be counterproductive in the LTC setting. Special diets for diabetes, hypertension and heart failure, and hypercholesterolemia have not been shown to improve control or affect symptoms. When a patient is at risk or has unintended weight loss, the presence of one of diagnoses alone is insufficient justification for continuing dietary restrictions. The reasons for any dietary restrictions that are ordered should be clearly stated in the patient's record.³⁵

ADA:

The Dietary Approaches to Stop Hypertension (DASH) eating pattern is known to reduce blood pressure and may also reduce rates of heart failure. The DASH diet is low in sodium and saturated fat but also high in calcium, magnesium, and potassium. The nutrition care plan for older adults with cardiac disease should focus on maintaining blood pressure and blood lipid levels while preserving eating pleasure and quality of life. Using menus that work toward the objectives of the Dietary Guidelines for Americans and/or the DASH diet can help achieve those goals.³⁶

CMS:

Dietary restrictions, therapeutic (e.g., low fat or sodium restricted) diets, and mechanically altered diets may help in select situations. At other times, they may impair adequate nutrition and lead to further decline in nutritional status, especially in already undernourished or at-risk individuals. When a resident is not eating well or is losing weight, the interdisciplinary team may temporarily abate dietary restrictions and liberalize the diet to improve the resident's food intake to try to stabilize their weight.³⁷

Relevant Research Trends

The effects of the traditional low cholesterol and low fat diets typically used to treat elevated cholesterol vary greatly and, at most, will decrease lipids by only 10-15%. If aggressive lipid reduction is appropriate for the nursing home resident it can be more effectively achieved through the use of medication that provides average reductions of between 30 and 40% while still allowing the individual to enjoy personal food choices.^{38, 39}

³⁵ AMDA Clinical Practice Guideline for Alteration in Nutritional Status, 2010, 20.

³⁶ ADA Position Paper Individualized Nutrition Approaches for Older Adults in Health Care Commun. 2010.

³⁷ CMS State Operations Manual Appendix P, Tag 325 Nutrition

³⁸ Randomised trial of cholesterol lowering in 4444 patients with coronary heart disease: the Scandinavian Simvastatin Survival Study (4S), *The Lancet*. 1994;344(8934):1383.

³⁹ LaRosa JC, Grundy SM, Waters DD, Shear C, Barter P, Fruchart JC, Gotto AM, Greten H, Kastelein JJ, Shepherd J, Wenger NK, Treating to New Targets (TNT) Investigators. Intensive lipid lowering with atorvastatin in patients with stable coronary disease. *N Engl J Med*. 2005;352(14):1425.

Recommended Course of Practice

Low saturated fat (low cholesterol) diets have only a modest effect on reducing blood cholesterol in the long term care elder population and therefore should only be used when benefit has been documented.

Recommended Course of Practice

- Diet is to be determined with the person and in accordance with his/her informed choices, goals and preferences, rather than exclusively by diagnosis.
- Assess the condition of the person. Assess and provide the person's preferred context and environment for meals, in other words the person's preferences, patterns and routines for socialization (i.e. eating alone or with others), physical support (i.e. adapted eating utensils, assistance with cartons/cutting or adapted w/c positioning), timing of meals (i.e. typical community or unique meal times) and personal meaning/value of the dining experience (i.e. for one who does not eat breakfast, breakfast is not important but perhaps an early lunch is). Include quality of life markers such as satisfaction with food, service received during meals, level of control and independence.
- Unless a medical condition warrants a restricted diet, consider beginning with a regular diet and monitoring how the person does eating it.
- Empower and honor the person first, and the whole interdisciplinary team second, to look at concerns and create effective solutions.
- Support self-direction and individualize the plan of care.
- Ensure that the physician and consultant pharmacist are aware of resident food and dining preferences so that medication issues can be addressed and coordinated i.e. medication timing and impact on appetite.
- Monitor the person and his/her condition related to their goals regarding nutritional status and their physical, mental and psychosocial well-being.
- Although a person may have not be able to make decisions about certain aspects of their life, that does not mean they cannot make choices in dining.
- When a person makes “risky” decisions, the plan of care will be adjusted to honor informed choice and provide supports available to mitigate the risks.
- Most professional codes of ethics require the professional to support the person/client in making their own decisions, being an active, not passive, participant in their care.
- When caring for frail elders there is often no clear right answer. Possible interventions often have the potential to both help and harm the elder. This is why the physician must explain the risks and benefits to both the resident and interdisciplinary team. The information should be discussed amongst the team and resident/family. The resident then has the right to make his/her informed choice even if it is not to follow recommended medical advice and the team supports the person and his/her decision, mitigating risks by offering support, i.e. offering foods of natural pureed consistency when one refuses recommended tube feeding. It is when the team makes decisions for the person without acknowledgement by all that

problems arise. The agreed upon plan of care should then be monitored to make sure the community is best meeting the resident's needs.

- All decisions default to the person.

Standard of Practice for Individualized Altered Consistency Diet

An altered consistency diet is usually prescribed due to swallowing difficulties, or dysphagia, which is not a diagnosis but rather a symptom commonly associated with conditions such as stroke, dementia or Parkinson's disease.

Basis in Current Thinking and Research

AMDA:

Swallowing abnormalities are common but do not necessarily require modified diet and fluid textures, especially if these restrictions adversely affect food and fluid intake.⁴⁰

Provide foods of a consistency and texture that allow comfortable chewing and swallowing. A resident who has difficulty swallowing may reject pureed or artificially thickened foods but may eat foods that are naturally of a pureed consistency, such as.... mashed potatoes, ... puddings, ... and yogurt, finely chopped foods may retain their flavor and be equally well handled (Ibid).

ADA:

The registered dietitian should collaborate with the speech-language pathologist and other healthcare professionals [such as the occupational therapist] to ensure that older adults with dysphagia receive appropriate and individualized modified texture diets. Older adults consuming modified texture diets report an increased need for assistance with eating, dissatisfaction with foods, and decreased enjoyment of eating, resulting in reduced food intake and weight loss.⁴¹

CMS:

In deciding whether and how to intervene for chewing and swallowing abnormalities, it is essential to take a holistic approach and look beyond the symptoms to the underlying causes. Excessive modification of food and fluid consistency may unnecessarily decrease quality of life and impair nutritional status by affecting appetite and reducing intake. Many factors influence whether a swallowing abnormality eventually results in clinically significant complications such as aspiration pneumonia. Identification of a swallowing abnormality alone does not necessarily warrant dietary restrictions or food texture modifications. No interventions consistently prevent aspiration and no tests consistently predict who will develop aspiration pneumonia.⁴²

⁴⁰ AMDA Clinical Practice Guideline for Alteration in Nutritional Status 2010, 20.

⁴¹ ADA Unintended Weight Loss Guideline 2009.

⁴² CMS State Operations Manual Appendix PP, 483.25 Tag F325 Nutrition.

Relevant Research Trends

Disease states which affect muscle strength and coordination alter the ability for one to successfully complete a swallow and/or protect the airway resulting in: 1) choking, where food partially or fully obstructs a resident's airway; or 2) aspiration or inhalation of food/liquids, oral secretions or gastric secretions into the airway and lungs which may result in pneumonia or pneumonitis.⁴³ In addition, problems with swallowing efficiency (weakness/fatigue/limited endurance) may lead to residue in the oral tract, incomplete swallowing and reduced intake.^{44, 45}

The anticipated outcome of solid foods ground or pureed and liquids thickened to nectar or honey thickness is improvement in oral intake and a reduced risk of choking and/or aspiration. However, data on their effectiveness is inconsistent; not all residents with dysphagia aspirate or choke and not all aspiration results in pneumonia.^{46, 47, 48} While a modified barium swallow may show that thickened liquids reduce the risk of aspiration acutely, there is little to no long term evidence that this intervention prevents aspiration pneumonia^{49, 50, 51}.

There is evidence that improved oral care can reduce the risk of developing aspiration pneumonia in the elderly.^{52, 53} In addition, oral care can impact clinical issues such as dehydration. For example, residents with swallowing problems may be able to have water

⁴³ Marik PE. Aspiration Pneumonitis and Aspiration Pneumonia. *N Eng J Med* 2001; 344; 9: 665-671.

⁴⁴ Kays, S. & Robbins, J. 2009. The application of tongue endurance measures to functional dining. *Perspectives on Swallowing and Swallowing Disorders (Dysphagia)*, 18, 61-67.

⁴⁵ Kays, S.A., Hind, J.A., Gangnon, R.E., & Robbins, J. 2010. Effects of dining on tongue endurance and swallowing-related outcomes. *Journal of Speech, Language, and Hearing Research*, 53, 898-907.

⁴⁶ Logeman JA, Gensler G, Robbins, et al. Design, Procedures, Findings, and Issues from the Largest NIH Funded Dysphagia Clinical Trial entitled Randomized Study of Two Interventions for Liquid Aspiration; Short and Long-term Effects. (Protocol 201) Presented at ASHA Annual Conference, November 16-18, 2006. Available at http://www.dysphagassist.com/major_randomized_studies. Accessed Dec 20, 2009.

⁴⁷ Robbins J, et al. Comparison of 2 Interventions for Liquid Aspiration on Pneumonia Incidence. *Ann Int Med* 2008; 148:509-518.

⁴⁸ Messinger-Rapport B, et al. Clinical Update on Nursing Home Medicine: 2009. *J Amer Med Dir Assoc* 2009; 10: 530-553.

⁴⁹ Logeman JA, Gensler G, Robbins, et al. Design, Procedures, Findings, and Issues from the Largest NIH Funded Dysphagia Clinical Trial entitled Randomized Study of Two Interventions for Liquid Aspiration; Short and Long-term Effects. (Protocol 201) Presented at ASHA Annual Conference, Nov. 16-18, 2006. Available at http://www.dysphagassist.com/major_randomized_studies. Accessed Dec 20, 2009.

⁵⁰ Robbins J, et al. Comparison of 2 Interventions for Liquid Aspiration on Pneumonia Incidence. *Ann Int Med* 2008; 148:509-518.

⁵¹ Messinger-Rapport B, et al. Clinical Update on Nursing Home Medicine. *J Amer Med Dir Assoc* 2009; 10: 530-553.

⁵² Sarin J, Balasubramaniam R, Corcoran AM, et al. Reducing the risk of aspiration pneumonia among elderly patients in long-term care facilities through oral health interventions. *J Am Med Dir Assoc*. 2008;9:128-135

⁵³ Yoon, M.N. & Steele, C.M. (2007). The oral care imperative: The link between oral hygiene and aspiration pneumonia. *Topics in Geriatric Rehabilitation*, 23, 280-288.

throughout the day (i.e. the Frazier free water protocol), as long as good oral care is provided.⁵⁴

Recent information also raises the concern that these at risk residents become more at risk for dehydration and malnutrition caused by the unpalatable and visually unappealing modified dysphagia diets.⁵⁵

Management of all geriatric conditions involves some risks. No known evaluations or interventions can guarantee that someone will not aspirate. It is important to note that many elderly individuals with swallowing abnormalities and aspiration risk do not get aspiration pneumonia. In fact, there is evidence that altered consistency diets may increase the risk of nutrition and hydration deficits. Thickened liquids and pureed foods are often poorly tolerated.⁵⁶

While there are currently no published studies that show that tube feeding prevents aspiration, one study found that orally fed patients with dysphagic disorders had significantly less aspiration than tube-fed patients.⁵⁷

Current Thinking

Given the complexity of the swallow mechanism and the multitude of problems that can arise, it is essential that the physician is involved in the evaluation of swallowing disorders. A thorough history and physical examination is required to determine potential causes of the swallowing dysfunction. While the most common processes causing dysphagia in long term care are related to identified, co-morbid conditions, it is important to consider other disease states or pathology such as previously undiagnosed mass lesions, gastroesophageal reflux, or cancer.⁵⁸

...the interdisciplinary team should assess dysphagia in the context of the whole individual. It is essential to understand who the resident is, and how he/she is doing medically, functionally and psychosocially.⁵⁹

If a medical evaluation identifies oral-pharyngeal dysphagia as a concern, a bedside swallow evaluation should be performed. This evaluation may provide valuable

⁵⁴ Panther, K. 2005. The Frazier free water protocol. *Perspectives on Swallowing and Swallowing Disorders (Dysphagia)*, 14, 4-9.

⁵⁵ Steele C. Food for Thought: Primum Non Nocere: The Potential for Harm in Dysphagia Intervention. *Perspectives on Swallowing and Swallowing Disorders (Dysphagia)*. 2006: 15: 19-23.

⁵⁶ Levenson, Steven. "Changing Perspectives on LTC Nutrition & Hydration." *Caring for the Ages*. September 2002, Vol. 3, No. 9, pp. 10-14. www.amda.com/publications/caring/september2002/nutrition.cfm

⁵⁷ Feinbert MJ, Knebl J, Tully J. Prandial aspiration and pneumonia in an elderly population followed over three years. *Dysphagia* 1996; 11; 104-109.

⁵⁸ Leible and Wayne, The Role of the Physician Order, paper written for CHII 2010.

⁵⁹ Levenson, S. The Basis for Improving and Reforming Long-Term Care, Part 3: Essential Elements for Quality Care, *J Amer Med Dir Assoc*, 2009: 10: 597-606.

information regarding the resident's swallowing function and efficiency. Results of this evaluation should be considered by the interdisciplinary team and recommendations regarding swallowing management, including diet modifications, should be made based upon concerns that have been raised and discussion with the resident and/or their family/POA regarding risks and benefits.⁶⁰

The use of videofluoroscopy or other instrumental swallowing assessments in long term care should be used only when clinically indicated. When used appropriately, these assessments can provide useful information about where problems are arising and potential modifications that may be of assistance to the resident. The results of these tests should be used in assisting the interdisciplinary team in discussing further options with the resident and or their family/Power of Attorney (POA). If the testing will not add new information or aid in adjusting the resident's plan of care then the value of the additional test needs to be reconsidered (Ibid).

Interdisciplinary team members, including health care practitioners, should be involved in balancing the risks of aspiration against the potential benefits of more liberal diets and food consistency, and deciding whether there are viable alternatives. There should be a discussion of the patient's progress, goals and objectives. Often, aspiration risks must be tolerated because of other, more immediate or probable risks such as nutrition or hydration deficits.⁶¹ (For this purpose of this document, healthcare practitioners refers to advanced practice nurses, physician assistants and physicians.)

Some physicians are writing orders for modified consistencies in ranges that accommodate each resident's differing acceptance/tolerance at different times of day, to different food groups such as "puree to mechanical soft" or "mechanical soft to soft."⁶²

A comprehensive and thorough assessment of the resident includes everything from medication side effects that reduce appetite to depression and beyond to ensure that the standard of care related to nutrition is provided. When all is ruled out and documented and the resident or family persists in refusal---this becomes the standard of care for that person. Ensuring thorough ongoing reassessment is of utmost importance in order to continually challenge the highest practicable level of functioning repeatedly over time, especially in the months following the original diagnosis as well as capturing that what a person wants can and does change over time (Ibid).

The risk of choking needs to be compared and weighed to the slow process of wasting away. We need to stop letting the risk-benefits default to the special diet. We're weighted on that side and not looking at that the person might waste away (CHII Recommendation).

⁶⁰ Leible and Wayne, The Role of the Physician Order, paper written for CHII 2010.

⁶¹ Levenson, Steven. "Changing Perspectives in LTC Nutrition and Hydration." Caring for the Ages. 9.3 2002 10-14.

⁶² Bump, Linda. Clinical Standards Task Force communication, 2011.

Recommended Course of Practice

- Diet is to be determined with the person and in accordance with his/her informed choices, goals and preferences, rather than exclusively by diagnosis.
- Assess the condition of the person. Assess and provide the person's preferred context and environment for meals, in other words the person's preferences, patterns and routines for socialization (i.e. eating alone or with others), physical support (i.e. adapted eating utensils, assistance with cartons/cutting or adapted w/c positioning), timing of meals (i.e. typical community or unique meal times) and personal meaning/value of the dining experience (i.e. for one who does not eat breakfast, breakfast is not important but perhaps an early lunch is). Include quality of life markers such as satisfaction with food, service received during meals, level of control and independence.
- Unless a medical condition warrants a restricted diet, consider beginning with a regular diet and monitoring how the person does eating it.
- Empower and honor the person first, and the whole interdisciplinary team second, to look at concerns and create effective solutions.
- Support self-direction and individualize the plan of care.
- Ensure that the physician and consultant pharmacist are aware of resident food and dining preferences so that medication issues can be addressed and coordinated i.e. medication timing and impact on appetite.
- Monitor the person and his/her condition related to their goals regarding nutritional status and their physical, mental and psychosocial well-being.
- Although a person may have not be able to make decisions about certain aspects of their life, that does not mean they cannot make choices in dining.
- When a person makes “risky” decisions, the plan of care will be adjusted to honor informed choice and provide supports available to mitigate the risks.
- Most professional codes of ethics require the professional to support the person/client in making their own decisions, being an active, not passive, participant in their care.
- When caring for frail elders there is often no clear right answer. Possible interventions often have the potential to both help and harm the elder. This is why the physician must explain the risks and benefits to both the resident and interdisciplinary team. The information should be discussed amongst the team and resident/family. The resident then has the right to make his/her informed choice even if it is not to follow recommended medical advice and the team supports the person and his/her decision, mitigating risks by offering support, i.e. offering foods of natural pureed consistency when one refuses recommended tube feeding. It is when the team makes decisions for the person without acknowledgement by all that problems arise. The agreed upon plan of care should then be monitored to make sure the community is best meeting the resident's needs.
- All decisions default to the person.

Standard of Practice for Individualized Tube Feeding

Basis in Current Thinking and Research

AMDA:

Tube feeding may be clinically appropriate in certain circumstances, but it should not be an automatic next step when other feeding strategies have failed. Before deciding to initiate tube feeding, the interdisciplinary care team should meet with the patient and family to carefully consider the risks and benefits of tube feeding and the patient's preferences.

Contrary to what many people think, tube feeding does not ensure the patient's comfort or reduce suffering; it may cause diarrhea, abdominal pain, and local complications and may increase the risk of aspiration.⁶³

ADA:

Enteral nutrition may not be appropriate for terminally ill older adults with advanced disease states, such as terminal dementia, and should be in accordance with advanced directives. The development of clinical and ethical criteria for the nutrition and hydration of persons throughout the life span should be established by members of the health care team, including the registered dietitian.⁶⁴

CMS:

In deciding whether and how to intervene for chewing and swallowing abnormalities, it is essential to take a holistic approach and look beyond the symptoms to the underlying causes. Excessive modification of food and fluid consistency may unnecessarily decrease quality of life and impair nutritional status by affecting appetite and reducing intake. Many factors influence whether a swallowing abnormality eventually results in clinically significant complications such as aspiration pneumonia. Identification of a swallowing abnormality alone does not necessarily warrant dietary restrictions or food texture modifications. No interventions consistently prevent aspiration and no tests consistently predict who will develop aspiration pneumonia. For example, tube feeding may be associated with aspiration, and is not necessarily a desirable alternative to allowing oral intake, even if some swallowing abnormalities are present.⁶⁵

Relevant Research Trends

Feeding tubes have not been shown to reduce the risk of aspiration or prolong survival in residents with end stage dementia.⁶⁶

⁶³ AMDA Clinical Practice Guideline for Alteration in Nutritional Status, 2010, 22.

⁶⁴ ADA Unintended Weight Loss Guideline, 2009.

⁶⁵ CMS State Operations Manual Appendix PP, 483.25 Tag F325 Nutrition

⁶⁶ Casarett D, Kapo J, Kaplan A. Appropriate Use of Artificial Nutrition and Hydration-Fundamental Principles and Recommendations. N Eng J Med 2005; 353;24: 2607-2612.

Oral secretions and/or gastric content are often the source of aspiration pneumonia or pneumonitis and thus will not be resolved with the placement of a tube.⁶⁷

Arguments for placing a tube for feeding include improving nutritional status. Studies in the elderly with dementia have shown little to no improvement in weight. In situations when there was improvement in weight, there was no improvement in clinical outcome for the residents. Enteral feeding is also considered for wound care as a means to improve wound healing. Data over a 6 month follow up has shown no impact on pressure ulcers or on infections such as cellulitis associated with wounds^{68, 69}.

Percutaneous endoscopic gastrostomy (PEG) and Percutaneous Endoscopic Jejunostomy (PEJ) tubes do not improve a resident's quality of life. There are associated physical and psychosocial discomforts related to the feedings themselves such as abdominal distension, diarrhea, and restriction of free movement if attached to an infusion device. Additionally, the resident is deprived of the social experience of mealtime that is valued by many. Placing a PEG tube in residents with advanced dementia should be strongly discouraged, and placement in other individuals should take goals of care into account.⁷⁰

A systematic literature search of 13 controlled trials on the use of supplements with people with dementia and 12 controlled trials testing assisted feeding showed high calorie supplements and other oral feeding options can help people with dementia to gain weight as an alternative to tube feeding.⁷¹

Due to a focus on food and their aromas "half a dozen residents have traded in their g-tubes for a place at the table" at Idylwood Care Center in Sunnyvale, California.⁷²

Methicillin-resistant *Staphylococcus aureus* (MRSA) colonization is more likely to be identified in residents with pressure ulcers or fecal incontinence or who are bed bound or require feeding tubes or urinary catheters.⁷³

Issues related to tube feeding are captured in this story from a family member: Rose had a stroke when she was 82 leaving her immobile, unable to speak clearly or feed herself. It was found that she was aspirating upon swallowing and of course her physician strongly recommended a permanent feeding tube. Despite her losses, Rose was very mentally clear

⁶⁷ Leible and Wayne, The Role of the Physician Order, paper written for CHII 2010.

⁶⁸ Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with dementia. Cochrane Database 2009 April 15; (2): CD007209.

⁶⁹ Finucane T, Christmas C, Travis K. Tube Feedings in Patients with Advanced Dementia: A Review of the Evidence. JAMA, Oct 1999; 1365-1370.

⁷⁰ Leible and Wayne, The Role of the Physician Order, paper written for CHII 2010.

⁷¹ Hanson, L.C., Ersek, M., Gilliam, R., and Carey, T. S. Oral Feeding Options for People with Dementia: A Systematic Review, JAGS 59: 463-472, 2011.

⁷² Schaeffer, Keith. Nourish the Body and Soul, Action Pact Publishing, 2008.

⁷³ Bradley S. Issues in the management of resistant bacteria in long-term care facilities. Infect Control Hosp Epidemiol 1999;20:362-6.

and strongly indicated she wanted no tubes! Her sister/power of attorney defended her choices and the physician reluctantly discharged her to skilled care with no tubes. Rose was hand fed pureed food and she did die of aspiration ... 7 years later.⁷⁴

Recommended Course of Practice

When there is weight loss and functional decline in an elder with multiple comorbidities or with end stage disease the default should not be to place a g-tube for nutrition and hydration. The interdisciplinary team including the elder's primary care physician should meet to address the elder's and or POA goals for care and develop a care plan that meets the changing needs of the elder. This may include a discussion regarding palliative care or hospice with the elder and the family.

- Diet is to be determined with the person and in accordance with his/her informed choices, goals and preferences, rather than exclusively by diagnosis.
- Assess the condition of the person. Assess and provide the person's preferred context and environment for meals, in other words the person's preferences, patterns and routines for socialization (i.e. eating alone or with others), physical support (i.e. adapted eating utensils, assistance with cartons/cutting or adapted w/c positioning), timing of meals (i.e. typical community or unique meal times) and personal meaning/value of the dining experience (i.e. for one who does not eat breakfast, breakfast is not important but perhaps an early lunch is). Include quality of life markers such as satisfaction with food, service received during meals, level of control and independence.
- Unless a medical condition warrants a restricted diet, consider beginning with a regular diet and monitoring how the person does eating it.
- Empower and honor the person first, and the whole interdisciplinary team second, to look at concerns and create effective solutions.
- Support self-direction and individualize the plan of care.
- Ensure that the physician and consultant pharmacist are aware of resident food and dining preferences so that medication issues can be addressed and coordinated i.e. medication timing and impact on appetite.
- Monitor the person and his/her condition related to their goals regarding nutritional status and their physical, mental and psychosocial well-being.
- Although a person may have not be able to make decisions about certain aspects of their life, that does not mean they cannot make choices in dining.
- When a person makes "risky" decisions, the plan of care will be adjusted to honor informed choice and provide supports available to mitigate the risks.
- Most professional codes of ethics require the professional to support the person/client in making their own decisions, being an active, not passive, participant in their care.
- When caring for frail elders there is often no clear right answer. Possible interventions often have the potential to both help and harm the elder. This is why

⁷⁴ Anna Ortigara, anecdotal family story, 4-2011.

the physician must explain the risks and benefits to both the resident and interdisciplinary team. The information should be discussed amongst the team and resident/family. The resident then has the right to make his/her informed choice even if it is not to follow recommended medical advice and the team supports the person and his/her decision, mitigating risks by offering support, i.e. offering foods of natural pureed consistency when one refuses recommended tube feeding. It is when the team makes decisions for the person without acknowledgement by all that problems arise. The agreed upon plan of care should then be monitored to make sure the community is best meeting the resident's needs.

- All decisions default to the person.

Please see the appendix as it includes an ethical case study involving tube feeding and a superb document regarding informed choice and who ultimately decides.

Standard of Practice for Individualized Real Food First

Basis in Current Thinking and Research

AMDA:

Provide foods of a consistency and texture that allow comfortable chewing and swallowing. A resident who has difficulty swallowing may reject pureed or artificially thickened foods but may eat foods that are naturally of a pureed consistency, such as ... mashed potatoes, ...puddings, ... and yogurt, finely chopped foods may retain their flavor and be equally well handled.⁷⁵

ADA:

Research suggests that the goal of food service should be to create a meal situation as natural and independent as possible, comparable with eating at home; making choices from a wide range of menu items tailored to the resident's wants; and seeking input from residents, family and staff. Stringent diet restrictions limiting familiar foods and eliminating or modifying seasonings may contribute to poor appetite; decreased food intake; and increased risk of illness, infection and weight loss.⁷⁶

CMS:

With any nutrition program, improving intake via wholesome foods is generally preferable to adding nutritional supplements.⁷⁷

CMS answers regarding choice to eat food out of a garden in the Survey and Certification memo S&C -07-07 December 21, 2006:

Question 2: (370) Approved Food Sources: You ask if the regulatory language at this Tag that the facility must procure food from approved food sources prohibits residents from any of the following: 1) growing their own garden produce and eating it; 2) eating fish they have caught on a fishing trip; or 3) eating food brought to them by their own family or friends.

Response 2: The regulatory language at this Tag is in place to prohibit a facility from procuring their food supply from questionable food sources, in order to keep residents safe. It would be problematic if the facility is serving food to all residents from the sources you list, since the facility would not be able to verify that the food they are providing is safe. The regulation is not intended to diminish the rights of specific residents to eat food in any of the circumstances you mention. In those cases, the facility is not procuring food. The residents are making their own choices to eat what they desire to eat. This would also be the case if a resident ordered a pizza, attended a ball game and bought a hot dog, or any similar circumstance. The

⁷⁵ AMDA Clinical Practice Guideline for Alteration in Nutrition, 2010.

⁷⁶ ADA Liberalization of the Diet Prescription Improves Quality of Life for Older Adults in LTC, 2005.

⁷⁷ CMS State Operations Manual Appendix PP 483.25(i) Tag F325 Nutrition 2008 Revised Guidance.

right to make these choices is also part of the regulatory language at F242, that the resident has the right to, “make choices about aspects of his or her life that are important to the resident.” This is a key right that we believe is also an important contributing factor to a resident’s quality of life.

Relevant Research Trends

An expectation of OBRA since 1987, choosing food before supplements, and food before medication is a natural decision in culture change. With choice, accessibility and individualization, our residents eat foods of choice throughout the day, and even during the night if need be, eliminating the need for costly, and often refused, commercial supplements. Similarly, the need for laxatives is reduced and often eliminated with increased fluid intake and increased opportunities for fiber rich, bowel stimulating foods of choice. Even the need for medication for behavioral management can be reduced when foods of choice are available at times of choice and places of choice.⁷⁸

Homes eliminating commercial supplements have found a significant increase in food consumption and reduced incidence of weight loss (Ibid).

Oral supplements..... often go wasted or conflict with medications. Improving taste is one of the best and simplest ways of improving nutrition.⁷⁹

An 11 week randomized controlled intervention study with 121 people living in nursing homes found improved nutrition and function with a multifaceted intervention of chocolate, homemade supplements, group exercise and oral care.⁸⁰

Oral liquid nutrition supplements have been shown to be only moderately successful in increasing energy intake, which has also been shown to be related to the limited time staff can devote to getting the supplements delivered and giving verbal encouragement to consume them.⁸¹

A randomized, controlled trial in three nursing homes with sixty three residents found offering residents a choice among a variety of foods and fluids twice per day may be a more effective nutrition intervention than oral liquid nutrition supplementation. Also found was that snack options are a more cost-effective nutrition intervention relative to supplements based on staff time, resident refusal rates, caloric intake and waste.⁸²

⁷⁸ Bump, Linda. Food for Thought. Action Pact Publishing. 2004-2005.

⁷⁹ Webster, Clint. Preventing Malnutrition in the Elderly. Final Research Papers, Winter 2008, March 4, 2008.

⁸⁰ Beck, A. M., Damkajaer, K. and Beyer, N. Multifaceted nutritional intervention among nursing home residents has a positive influence on nutrition and function. Nutrition, 24, 2008,1073-1080.

⁸¹ Schlettwein-Gsell, D. “Nutrition and the quality of life: A measure for the outcome of nutritional intervention?” American Journal of Clinical Nutrition, Vol. 556, 1992, pp. 12635-12665.

⁸² Simmons, Sandra F., Zhuo, X., Keeler, E. Cost-effectiveness of Nutrition Interventions in Nursing Home Residents: a pilot intervention. The Jour of Nut, Health and Aging Vol. 14 No. 5 2010 367-372.

Historically, it has been shown that giving people foods they like to eat minimizes the use of supplements and can reduce costs. For example, Eric and Margie Haider, administrator and director of nursing at Crestview Nursing Home in Missouri in 2001, espoused that by giving people foods they like to eat, you can minimize the use of supplements and calculated a savings of \$1,164.00 per month by serving real foods residents wanted to eat.⁸³ Supplements at Crestview went from 72 in 1998 to only 14 by July 2000.⁸⁴

One study revealed that among 100 frail nursing home residents, oral protein supplements did not produce improvement in measures of strength or function unless it was combined with resistance strength training.⁸⁵

Reducing the number of medications that a resident takes can also impact appetite. Residents that must take numerous pills or large volumes of liquid at each med-pass, with bulk laxatives, for example, can have reduced appetite at meal time.⁸⁶

Elderly people who have one or more medical conditions and are taking an average of three medications show greater losses of taste sensitivity than healthy, older adults.⁸⁷ Flavor enhancement of nutrient dense food may compensate for taste losses and improve food intake. Flavor enhancers are mixtures of odorous molecules that are extracted from natural products or synthesized, such as monosodium glutamate. Flavor enhancement differs from adding spices, herbs, and salt because flavor enhancement intensifies the flavor of food while spices and herbs increase odor and taste sensation. Studies involving frail elderly have shown that adding flavor enhancers to food improved intake and immune function by increasing the total number of lymphocytes, resulting in improved functional status.⁸⁸

Current Thinking

Before any nutritional supplement is offered let alone “ordered,” providers and surveyors ensure that real foods were offered first (CHII Recommendation).

⁸³ Bowman, Carmen S. The Environmental Side of the Culture Change Movement: Identifying Barriers and Potential Solutions to furthering Innovation in Nursing Homes. Background Paper to the April 3rd, 2008 Creating Home in the Nursing Home: A National Symposium on Culture Change and the Environment Requirements. Report of CMS Contract HHSM-500-2005-00076P.

⁸⁴ Rantz, Marilyn J., and Marcia K. Flesner. Person Centered Care: A Model for Nursing Homes. American Nurses Association: Washington D.C., 2004, pp. 23, 25.

⁸⁵ Fiatarone MA, O'Neill MF, Ryan ND, et al. Exercise training and nutritional supplementation for physical frailty in very elderly people. *N Engl J Med*, 1994; 330; 1769-1775.

⁸⁶ Martin, McHenry Caren. The Consultant Pharmacist's Expanded Role in Nutrition Management. *The Consultant Pharmacist*. June 2009. Vol. 24. No. 6.

⁸⁷ Shiffman SS, Graham BG, Taste and smell perception affect appetite and immunity in the elderly. *Euro Clin Nutr* 2000; 54, 3: 54-63.

⁸⁸ Shiffmann SS, Intensification of sensory properties of foods for the elderly. *J Nutr* 2000; 130 Suppl 4; 927-930.

Some homes are finding alternatives to dietary supplementation by engaging the elders in growing their own garden. The elders choose what will be grown, help with the planting, tending and harvesting. Then they help prepare and eat the harvest. Besides the nutritional benefit, the elders also have the benefit of accomplishment and contribution which affects their mood and self-esteem.⁸⁹

Recommended Course of Practice

Advocate the use of real food before the addition of dietary supplements.

Recommend using real food before any modified foods including laxative mixtures or single source nutrient powders/liquids.

Instead of artificial supplements, extra protein, vitamin and fiber powders can be added to smoothies, shakes, malts and other real foods people like to eat.

Use of fresh produce is encouraged, an example would be produce from resident gardens.

The dining experience should be as natural as possible comparable to eating at home.

Resident satisfaction with the quality of the food and the dining experience should be a home's priority.

⁸⁹ Hyde, Denise. The Role of the Pharmacist. Paper for CHII.

Standard of Practice for Individualized Honoring Choices

Many homes are offering the people who live there more dining choices based on the individual's life patterns, history and current preferences. Including but not limited to open dining times, choice from menus, buffets, family dining style with food at the table and snack bars/accessible pantries. Honoring choice is a complex issue including variables such as balancing risk with benefit, individual decision making capacity, and inclusion of resident advocates. Honoring choice is born out of relationship, consistent resident staff relationships are essential to identifying and honoring individual choice.

Basis in Current Thinking and Research

AMDA:

Most residents will appreciate having these choices and the team can weigh the benefits against the risks and work with the resident and/or family/POA to establish an effective individualized plan of care.⁹⁰

Identifying the proper balance between medical complexity, which may require medications, modifications and restrictions, and allowing for personal choice, is the essence of good medicine. However, a blanket or rote approach to these issues (for example, easing restrictions on everyone without regard to impact) is inconsistent with sound approaches. Individualized care should seek to understand the entire person, to focus attention on the medical, functional and psychosocial aspects of the resident. The interdisciplinary team should consider the potential effects of proposed interventions on the resident, rather than simply the treatment or protocol's effect on a disease. For example, some residents who remain in bed until they awake on their own may develop pressure ulcers or lose weight, although most will not. Most residents will appreciate having these choices and the team can weigh the benefits against the risks and work with the resident and/or family/POA to establish an effective individualized plan of care. This approach is especially helpful in situations where the benefits of the intervention are modest and the risks significant.⁹¹

ADA:

Involving individuals in choices about food and dining such as food selections, dining locations, and meal times can help them maintain a sense of dignity, control, and autonomy.⁹²

Including older individuals in decisions about food can increase the desire to eat and improve quality of life (Ibid).

⁹⁰ AMDA The Role of the Medical Director in Person-Directed Care White Paper, Mar. 2010, 3.

⁹¹ AMDA The Role of the Medical Director in Person-Directed Care White Paper, Mar. 2010, 3.

⁹² ADA Position Paper Individualized Nutrition Approaches for Older Adults in Health Care Communities, 2010.

CMS:

Tag F242 Self-Determination and participation - The resident has the right to:

- 1) Choose activities, schedules, and health care consistent with his/her interests, assessments and plans of care;
- 2) Interact with members of the community both inside and outside the facility; and
- 3) Make choices about aspects of his or her life that are significant to the resident.

Providers are to be actively seeking preferences, choice over schedules important to the resident i.e. waking, eating, bathing, retiring and states if resident is unaware of the right to make such choices determine if home has actively sought resident preference information shared with caregivers.⁹³

Tag F280 Participation planning care and treatment – The resident has the right to - unless adjudged incompetent or otherwise found to be incapacitated under the laws of the State, participate in planning of care and treatment or changes in care and treatment.

Sometimes, a resident or resident’s representative decides to decline medically relevant dietary restrictions. In such circumstances, the resident, facility and practitioner collaborate to identify pertinent alternatives. [The resident or representative] has the right to make informed choices about accepting or declining care and treatment.⁹⁴

The right to make informed decisions means that the patient or patient’s representative is given the information needed in order to make “informed” decisions regarding his/her care.⁹⁵

Relevant Research Trends

Nursing home residents value control and choice on aspects of their daily lives including food.^{96, 97, 98}

Residents consumed a greater proportion of food when they were fed by CNAs who had less need for power and allowed the resident to control the interaction.⁹⁹

⁹³ CMS State Operations Manual Appendix PP, 483.15(b) Tag 242 Self-determination and participation.

⁹⁴ CMS State Operations Manual Appendix PP 483.25(i) Tag F325 Nutrition.

⁹⁵ CMS State Operations Manual Appendix A Hospitals Survey Protocol, Regulations and Interpretive Guidelines for Hospitals, A-0049 482.13(b)(2).

⁹⁶ Kane, R.A. et al. “Everyday Matters in the Lives of Nursing Home Residents: Wish for and Perception of Choice and Control,” *Journal of the American Geriatrics Society*, 45, No. 9, 1997, 1086-1093.

⁹⁷ Evans BC and Crogan NL. Using the FoodEx-LTCto assess institutional food service practices through nursing home residents’ perspectives on nutrition care. *J Gerontol Med Sci*, 2005, 60A, 125-128.

⁹⁸ West GE, Oullet D & Oulette S. Resident and staff ratings of foodservices in long-term care: implications for autonomy and quality of life. *J Appl Gerontol* 2003; 22 (1), 57-75.

⁹⁹ Mezey M, Fulmer T, Amella, E. Factors Influencing the Proportion of Food Consumed by Nursing Home Residents with Dementia. *Journal of the American Geriatrics Society*, Volume 47, Issue 7, Nov. 1999.

Autonomy in relation to food such as access to food between meals and having foods brought in by family and friends has a positive association with quality of life for residents.¹⁰⁰

When residents were asked to make a list of those aspects of their lives that were most important to their quality of life, they identified choice of dining companions and where to eat their meals as their top priorities.¹⁰¹

Bulk food service (steam table/buffet) and a home-like environment optimize energy intake in individuals at high risk for malnutrition, particularly those with low body mass index and cognitive impairment.¹⁰²

Snacking is an important dietary behavior among older adults... (and) may ensure older adults consume diets adequate in energy. Snacks provide over 25% of resident energy intake and 14% of protein intake.¹⁰³

Making food available 24 hours a day is recommended in the 2000 *Malnutrition and Dehydration in Nursing Homes: Key Issues in Prevention and Treatment* research study as one approach to the prevention and treatment of malnutrition and dehydration in nursing home residents.¹⁰⁴

Persons with mild to moderate cognitive impairment (i.e. Mini Mental State Exam scores 13-26) are able to respond consistently to questions about preferences, choices and their own involvement in decisions about daily living, and to provide accurate and reliable responses to questions about demographics.¹⁰⁵

¹⁰⁰ Carrier N, West GE, Ouellet D. Dining experience, foodservices and staffing are associated with quality of life in elderly nursing home residents. *The Journal of Nutrition, Health and Aging*, Vol. 13, No. 6, 2009. 565-570.

¹⁰¹ Cohn J & Sugar JA. Determinants of quality of life in institutions: perceptions of frail older residents, staff and families. In: Burren JF, Lubben JF, Rowe JC & Deutschman DE, *The concept and measurement of quality of life in the frail elderly*. Academic Press, Inc. Chapter 2.

¹⁰² Desai et al, *Changes in Types of Foodservice and Dining Room Environment Preferentially Benefit Institutionalized Seniors with Low Body Mass Index*, 2007.

¹⁰³ Zizza, C.A., F.A. Tayie, and M. Lino. "Benefits of Snacking in Older Americans." *Journal of the American Dietetic Association*, Vol. 107, 2007, 800-806.

¹⁰⁴ Burger, S.G. J Kayser-Jones and J. P. Bell *Malnutrition and Dehydration in Nursing Homes: Key Issues in Prevention and Treatment* The Commonwealth Fund 2000.

¹⁰⁵ Feinberg, Lynn Friss and Carol J Whitlatch, Are Persons with Cognitive Impairment able to State Consistent Choices? *The Gerontologist*, Vol. 41, No. 3, 374-382.

There is no way of knowing whether family surrogates, formal or informal, accurately represent the wishes of the older person with dementia.¹⁰⁶ Family members' and older residents' ratings of the services of both nursing homes and assisted living facilities reveal little congruence.^{107, 108}

Current Thinking

Choice of food has a tremendous impact on quality of life. Some might say it defines quality of life.¹⁰⁹

Foods of choice are available whenever residents are hungry, not just at scheduled meal times. And when they long for a specific food, it is available. Foods of choice are available 24/7 and someone is available 24/7 to prepare them.¹¹⁰

Simply speaking, it is all about choice. It is as simple as asking, "What does the resident want? How did they do it at home? How can we do it here?" Choice of what to eat, when to eat, where to eat, whom to eat with, how leisurely to eat. True choice, not token choice. Not the win-lose choice between a hot breakfast and sleeping to the rhythm of your day. Not simply the choice of hot or cold cereal, but also the raisins and brown sugar that make oatmeal a daily pleasure. For dining, true choice is exemplified in point-of-service choice... (Ibid).

Develop approaches to dining that reflect a view of elders as capable of making choices and deciding what, when, and with whom to dine as a mental wellness activity because it "exercises" the decision making circuitry of the brain, enhances pleasure, and strengthens memory encoding and retrieval.¹¹¹

There needs to be a new "red flag" or "assumption" for both surveyors and providers that a tray line or set/limited meal times are now viewed as an obvious contradiction of choice and if this lack of choice leads to failure to thrive it would be considered harm during the survey process (CH recommendation).

There needs to be another new "red flag" whereby any notation in a resident record or care plan of a resident as "non-compliant" with physician orders is viewed as an obvious contradiction to resident choice with a shift to facility non-compliance with requirements to offer choice at tag 242, right to refuse treatment at tag 155 and right to same rights as any citizen of the United States at Tag 151 (CHII Recommendation).

¹⁰⁶ Kane, R.L. and R.A. Kane, "What Older People Want from Long-Term Care And How They Can Get It." Health Affairs Nov./Dec. 2001

¹⁰⁷ Kane, R.A. et al, First Findings from Wave 1 Data Collection: Measures, Indicators and Improvement of Quality of Life in Nursing Homes (Minneapolis: Division of Health Services Research and Policy, School of Public Health, University of Minnesota, 2000..

¹⁰⁸ Levin, C.A. Resident and Family Perspectives on Assisted Living. Doctoral Thesis, Univ. of Minnesota, 2001.

¹⁰⁹ Leible and Wayne, The Role of the Physician Order, paper written for CHII 2010.

¹¹⁰ Bump, Linda. The Deep Seated Issue of Choice, paper for CHII 2010.

¹¹¹ Ronch, Judah. Food for Thought paper for CHII 2010.

Everyone, provider community, all disciplines, MDS Coordinators identify in assessment and on care plans a person's preferences more so than problems, distinguishing between true medical problems and personal preferences using the new guidance at Tag 242 "actively seeking preferences" to guide all of us. Create a new standard of practice that care plans identify familiar and meaningful foods preferred (CHII Recommendation).

The majority of nursing home residents are able to reliably answer questions about their satisfaction with the food service, regardless of cognitive status, and the presence of complaints is related to poor meal intake and depressive symptoms.¹¹²

Informed choice implies that someone informed the person, this is the facility's responsibility: risks of certain choices, benefits of certain choices, education. However, it now sounds like what we've been teaching to be the risks of choosing not following a certain restricted diet may not be true after all. If there is no evidence that restricted diets actually bring about the outcomes we thought they did, then we really do not know. Better yet would be basing probability on what the individual's baseline and history shows risk for that person to be.¹¹³

The medical director should work closely with the registered dietitian, director of nursing and the director of food services to develop a system promoting resident choice while maintaining quality of care. This system should include policies that promote routine use of a regular diet while maintaining opportunities for discussion of the risks and benefits of diet choices that are felt, by convention, to place the resident at risk. The facility must provide evidence of the education that was offered to the resident and the family as well as documentation of the discussion of the risks. A periodic review of the risks associated with the resident's choices should be conducted with the resident and his/her family. It is imperative the resident's physician be involved in these discussions.¹¹⁴

The facility should attempt to offer less risky alternatives to food choices the resident may request. Offering ice cream instead of a cookie may satisfy the desire for a dessert while maintaining a safer consistency. The facility must plan for the resident's choice, noting ways to monitor and provide for safety, such as offering to cut meat into small pieces at meals, recognizing the resident's ability to decline the offer. An informed consent by the resident does not mitigate the facility's responsibility to keep the resident as safe as the resident and his/her family allow based on informed choice (Ibid).

Defining Health-Related Quality of Life Subjective

¹¹² Simmons, Sandra F., Patrick Cleeton, and Tracey Porchak. "Resident Complaints about the Nursing Home Food Service: Relationship to Cognitive Status." *Journal of Gerontology: Psychological Sciences*, Vol. 10, 2009.

¹¹³ Bowman, Carmen. *The Food and Dining Side of the Culture Change Movement: Identifying Barriers and Potential Solutions to furthering Innovation in Nursing Homes Background Paper for the Feb. 2010 CHII*. Report of CMS Contract HHSM-500-2009-00057P.

¹¹⁴ Leible and Wayne, *The Role of the Physician Order*, paper written for CHII 2010.

Measured from the patient's perspective after informed education about illness and therapy (emphasis added)

Multidimensional sense of well-being (commonly agreed on by authors)

Functional well-being: energy level and ability to participate in activities of daily living, including work and leisure

Emotional: comprises both positive (peace of mind, happiness) and negative (depression, anxiety) moods

Physical well-being: body symptoms of pain, dyspnea, dysphagia, nausea, fatigue

Treatment satisfaction (emphasis added): includes financial costs

Social functioning: the ability to engage in social activities

Intimacy: concerns of body image and sexuality

Family well-being: ability to maintain communication and family relationships.¹¹⁵

The elder's right to have a liberalized diet or even the elimination of caloric and other dietary restrictions has slowly been embraced to enhance quality of life. But many ... interdisciplinary team[s] resist the elder's right to have an informed refusal of an ordered diet (texture modified or tube feeding) that might put them at aspirative and choking risk. Often this is based upon the long held, preconceived notion that federal regulatory requirements (and possibility of a deficiency finding) are for safety first, and quality of life decisions take a second seat after that. It is also based upon years of NOT informing the resident that these choices were his/her rights and NOT including the resident's voice or preference in the dietary planning and decision making. Yet, the F tag 151 federal requirement states its intent regarding the facility's responsibilities toward rights: "Exercising rights means that residents have autonomy and choice, to the maximum extent possible, about how they wish to live their everyday lives and receive care." This includes the right of refusal of an ordered medical therapy or diet. The surveyor is to "Pay close attention to resident or staff remarks and staff behavior that may represent deliberate actions to promote or to limit a resident's autonomy or choice." Each facility must answer the questions: How is the resident informed about dietary/dining rights? Does the resident have a voice or is it limited? Is there educating and informing the resident about alternatives and consequences of choices? Is there a mutually agreed upon plan recognizing the resident's choice? Is there adequate resident support and monitoring once that informed refusal is made? Remember the challenges when there were federal mandates of removing physical and chemical restraints for a resident's quality of life? There will always be safety issues and concerns. We are facing some of the same challenges in supporting a resident's informed refusal and right of choice.¹¹⁶

Put resident choice before regulations and guidelines such as Recommended Daily Allowances which are generic estimated nutritional needs and non-individualized (CHII Recommendation).

¹¹⁵ McMahon, MM, Hurley, DL, Kamath, PS, Mueller, PS. Medical and Ethical Aspects of Long-term Enteral Tube Feeding. Mayo Clin Proc Nov. 2005;80(11):1470
mayoclinicproceedings.com/content/80/11/1461.full.pdf

¹¹⁶ Handy, Linda. Culture Change in Dining and Regulatory Compliance, www.handydietaryconsulting.com 2011.

Residents who have capacity to decide should not be denied the choice to eat hot dogs or grapes whole which many homes and companies are imposing to minimize the potential choking risk (CHII Recommendation).

“I’m a firm believer in the rights of elders to do whatever the hell they want. If you only have the right to make the ‘good, wise’ decisions that your grown daughter agrees with, then you’re not running your own life anymore. I’ve taken care of lots of people who didn’t even know their own children. Sure, they probably shouldn’t be making decisions about their 401(k) plans, but they can decide what to wear and what to eat and whether to go outside on a daily basis. People think that if old people cannot make the big decisions, they cannot make any decisions—and that is just wrong. They have the right to folly.”¹¹⁷

Provide education to the whole clinical team on how to negotiate risk with the Elder when their life goals are contrary to best medical practices. Health care professionals need education in determining nutritional risk, conducting comprehensive nutritional assessments, developing and executing nutritional interventions, and evaluating nutritional outcomes. We need to make sure that the risks and the benefits are being discussed with residents at the same time that we’re asking for their choices and preferences (CHII Recommendation).

When caring for frail elders there is often no clear right answer. Possible interventions often have the potential to both help and harm the elder. This is why the physician must ... explain the risks and benefits to both the resident and interdisciplinary team. The information should be discussed amongst the team and resident/family and only then should an agreed upon choice be made. It is when the team makes decisions for the person without agreement by all that problems arise. The agreed upon plan of care should then be monitored to make sure the community is best meeting the resident's needs.¹¹⁸

Recommended Course of Action

Choices with meaningful options in accordance with the person’s preferences are offered to each resident numerous times daily, i.e. when to awaken, when to eat, what to eat, where to eat, what to do, when to bathe, when to retire, what to wear, etc.

A variety and increased number of staff present in the dining room enables both physical and psychosocial needs to be met. Additionally, staff can enhance and honor the individual choices for all residents reflective of preferences.

¹¹⁷ Dr. William Thomas as reported by Brown, Nell Porter. “At Home with Old Age Reimagining Nursing Homes” Harvard Magazine November – December 2008 The Alumni, <http://harvardmagazine.com/2008/11/at-home-with-old-age.html>. Accessed 10/15/09.

¹¹⁸ Wayne, Matthew. Clinical Standards Task Force communication, 2011.

There needs to be a new “red flag” or “assumption” for both surveyors and providers that a tray line or set/limited meal times are now viewed as an obvious contradiction of choice and if this lack of choice leads to failure to thrive it would be considered harm during the survey process (CHII recommendation).

Residents’ individual choices are actively sought after, care planned and honored, as Tag F 242 requires, based on life patterns, history and current preferences.

Team members of all disciplines and MDS Coordinators identify in assessment and on care plans a person’s preferences more so than problems, distinguishing between true medical problems and personal preferences using the new guidance at Tag 242 “actively seeking preferences” to guide all team members. Create a new standard of practice that care plans identify familiar and meaningful foods preferred (CHII Recommendation).

There needs to be another new “red flag” whereby any notation in a resident record or care plan of a resident as “non-compliant” with physician orders is viewed as an obvious contradiction to resident choice with a shift to facility non-compliance with requirements to offer choice at Tag 242, right to refuse treatment at Tag 155 and right to same rights as any citizen of the United States at Tag 151 (CHII Recommendation).

Instead of labeling one as “non-compliant,” nurses work with physicians to eliminate “orders” for restrictive diets residents don’t eat and instead create plans with the person that work for the person (see standards for various diets in Diet Liberalization section).

When caring for frail elders there is often no clear right answer. Possible interventions often have the potential to both help and harm the elder. This is why the physician must be present [involved] in order to explain the risks and benefits to both the resident and interdisciplinary team. The information should be discussed amongst the team and resident/family and only then should an agreed upon choice be made. It is when the team makes decisions for the person without agreement by all that problems arise. The agreed upon plan of care should then be monitored to make sure the community is best meeting the resident's needs.¹¹⁹

Provide education and support to anyone speaking on behalf of the resident, including health care professionals, families, friends, and legal representative on their obligation in advocating for the resident’s/the person’s individual life patterns, history, current preferences, opinions and wishes (not necessarily their own). Education should be inclusive so that the representatives clearly see their role as an advocate for the individual’s choice (not necessarily their own).

We do not assume that just because a resident may not be able to make decisions in some parts of their life they cannot make choices related to their dining preferences. Education,

¹¹⁹ Wayne, Matthew. Clinical Standards Task Force communication, 2011.

good observational skills, strong advocacy and consistent relationships with caregivers enables a person with impaired decision making capacity to make choices.

When making dining decisions that can be viewed as a risk to the individual's physical health, the plan of care will be adjusted to honor choice and provide the supports available to mitigate the risks based upon the individual's life goals.

Put resident choice before regulations and guidelines such as Recommended Daily Allowances which are generic estimated nutritional needs and non-individualized (CHII Recommendation).

Resident preferences in dining will be communicated to the entire interdisciplinary team so that medications and treatments, schedules and food offered at activities are consistent with choices honoring personal preferences.

Resident dining profiles (tray tickets) should be limited to adapted equipment, allergies, consistency modification and unique dietary needs. Preferences should be sought after as choices are offered (not just once and then recorded on a tray ticket indefinitely).

Standard of Practice for Shifting Traditional Professional Control to Individualized Support of Self Directed Living

Basis in Current Thinking and Research

AMDA:

Person-directed care promotes resident choice and self-determination in ways that are meaningful to the resident. It has been a key component of geriatric medicine for decades. The interdisciplinary team and the medical director have essential roles both in facilitating this process as well as in monitoring it for desired outcomes. Medical directors and clinicians should help nursing home administration and staff understand how to provide person-directed care while maintaining clinical excellence. To ensure success, nursing home leadership must support these efforts.¹²⁰

ADA:

Despite the growing body of evidence discouraging the use of therapeutic diets in older adults, these diets are still regularly prescribed. Research has not demonstrated benefits of restricting sodium, cholesterol, fat, and/or carbohydrate in older adults.¹²¹

CMS:

Residents have the right to refuse treatment, CMS Tag F151.

Residents have the right to informed choice, CMS Tag F325.

Residents have the right to choice, CMS Tag F242.

Pioneer Network/Hartford Institute for Geriatric Nursing:

Nurse Competencies for Nursing Home Culture Change –

#2 – Creates systems and adapts daily routines and “person-directed” care practices to accommodate resident preferences.

#4 – Evaluates the degree to which person-directed care practices exist in the care team and identify and addresses barriers to person-directed care.

#9 – Problem-solves complex medical/psychosocial situations related to resident choice and risk.

#10 – Facilitates team members, including residents and families, in shared problem-solving, decision making and planning.

Related Research Trends

As we know that residents have their very individual biography of nutrition and are experts in preparing meals, the cook meets every week with small groups of residents discussing a variety of food- and meal- related topics. The idea is the cook gets to know each individual resident and learns about their wishes, their expectations, their skills, and their expertise.... What we observe in these settings is that life becomes normal, livelier,

¹²⁰ AMDA The Role of the Medical Director in Person-Directed Care White Paper, Mar. 2010, 5.

¹²¹ ADA Position Paper Individualized Nutrition Approaches for Older Adults in Health Care Communities 2010.

that residents eat much better and that loneliness, helplessness and monotony are reduced. Residents need less medicine and sleep much better.¹²²

Current Thinking

... the people with the power remain the biggest barrier to meaningful culture change in long-term care. They are too easily satisfied. Even as they gravitate toward this new way, their old way of thinking is so strong it keeps leaders from truly changing the organization and empowering teams. The old mindset makes us way too satisfied with the low-hanging fruit – those positive outcomes that inevitably result from even modest changes. Because even small improvements are so much better than the old way, it is easy to become complacent and avoid the really difficult work necessary to create true home for elders.¹²³

Unfortunately, these evidence based guidelines are not yet widely accepted as standards of practice, and even more unfortunately, standards of traditional best practice developed for individuals at earlier stages of the life cycle are currently applied to elders, often limiting their choices, limiting their quality of life, while well-meaning practitioners practice a medical model of care (Ibid).

Life extension with medically advanced treatments or imposed chronic condition management at an advanced age negating choice or satisfaction often leads to negative outcomes that are then managed with more liberal approaches that should have been the approach from the beginning (Ibid).

Establish guidelines that define an elder's right to make an unpopular or ill-advised decision in view of all available information about the impact of the decision on his/her future self ("the right to folly") versus cognitive, emotional or other conditions that render him/her vulnerable to exploitation, abuse or neglect. This should be based on imagining future scenarios that result from the decision and how the elder appreciates and plans for the impact on his/her well being.¹²⁴

We all need to shift to agreeing that care givers will offer to do what is clinically best for a person and if the person refuses, that's okay. Along with liability comes responsibility to the person we're serving – if an elder decides to not eat what is clinically best we work with them but never force them – caring for someone doesn't mean you have to make the choices for them (CHII Recommendation).

Another level of education is needed for clinicians and care givers to be able to shift traditional professional control over to the resident since it feels like we're going against what we have believed to be our obligation or even a nursing license of what "good care" is

¹²² Hoffmann, AT. Quality of Life, Food Choice and Meal Patterns – Field Report of a Practitioner. Ann, Nutr Metab 2008; 52 (suppl 1): 20-24.

¹²³ Bump, Linda. The Deep Seated Issue of Choice paper for CHII Feb. 2010.

¹²⁴ Ronch, Judah. Food for Thought: The Missing Link between Dining and Positive Outcomes, paper for CHII 2010.

which we now realize has been making decisions for residents and not honoring their decisions (CHII Recommendation).

Self-directed living includes honoring the resident's choice even in the face of family disagreement. Power of Attorney does not give the right to demand restricted diets or altered consistencies. Even with a guardianship, a family member should work closely with the physician to assess all risks including the risk of more restrictive choice, or in other words, of not honoring the resident's choice (CHII Recommendation).

At times the life goals should supersede medical best practices. Recommendations should be based on what each elder wants, not what we would want for ourselves or what we think the elder wants.¹²⁵

While alcohol is not a medical treatment it may present certain risks. It is for some elders a lifestyle choice. Due to potential for interactions with medications and certain clinical conditions the elder's physician should be consulted regarding the elder's choice to enjoy an alcoholic beverage. If there are concerns regarding medications or effects on illness there is a opportunity to provide information to the elder or his/her family about the potential risks. The clinician may choose to make changes in the medication regimen to address potential concerns. There is an opportunity to offer non-alcoholic drinks when the risks are considered to be higher than the potential benefit. It the elder and his or her family's right to make an informed choice.¹²⁶

If the patient is sufficiently informed about the risks and benefits of acceptance (informed consent) or refusal (informed refusal) of a proposed intervention or treatment and refuses, the clinician should respect the patient's decision (Mayo Clinic Proceedings 2005).¹²⁷

Recommended Course of Action

All decisions default to the person.

¹²⁵ Hyde, Denise. The Role of the Pharmacist paper written for the CHII 2010.

¹²⁶ Power, Al. The Physician and Person-Directed Dining, unpublished, April 2011.

¹²⁷ McMahon, MM, Hurley, DL, Kamath, PS, Mueller, PS. Medical and Ethical Aspects of Long-term Enteral Tube Feeding. Mayo Clinic Proceedings Nov. 2005; 80(11): 1461-1476.

New Negative Outcome

Basis in Current Thinking and Research

AMDA:

“Person-directed care” is a philosophy that encourages both older adults and their caregivers to express choice and practice self-determination in meaningful ways at every level of daily life. Values that are essential to this philosophy include choice, dignity, respect, self-determination and purposeful living. These values also are at the core of desirable medical care and are embraced by many medical providers. Yet practices that conflict with these principles are common in the long term care setting. Examples include awaking residents at times that are determined by staff convenience, modifying residents’ diets without discussion, and inflexible meal times and medication pass times. In addition, care plans may be created without truly understanding a resident, their history or previous occupation, their recreational and personal preferences, wishes regarding life-sustaining treatment, and other likes and dislikes. Geriatrics is a discipline that emphasizes medical care in the proper context, including its impact on function, quality of life, and personal preferences.¹²⁸

ADA:

For many older adults residing in health care communities, the benefits of less-restrictive diets outweigh the risks. When considering a therapeutic diet prescription, a health care practitioner should ask: Is a restrictive therapeutic diet necessary? Will it offer enough benefits to justify its use?¹²⁹

CMS:

Tag F325 Nutrition, Deficiency Categorization

Severity Level 4 - Immediate Jeopardy:

Substantial and ongoing decline in food intake resulting in significant unplanned weight loss due to dietary restrictions or downgraded diet textures (e.g., mechanic soft, pureed) provided by the facility against the resident’s expressed preferences.

Severity Level 3 - Actual Harm:

Unplanned weight change and declining food and/or fluid intake due to the facility’s failure to assess the relative benefits and risks of restricting or downgrading diet and food consistency or to obtain or accommodate resident preferences in accepting related risks;

¹²⁸ AMDA The Role of the Medical Director in Person-Directed Care White Paper, Mar. 2010, 1.

¹²⁹ ADA Position Paper: Individualized Nutrition Approaches for Older Adults in Health Care Communities, 2010.

Current Thinking

Professional standards direct nurses to act to *prevent unsafe, illegal, and unethical practices* and protect patients who may be at risk.¹³⁰ Nurses are educated to look for errors in medication and treatment orders, and to look for adverse outcomes related to medication and treatments. When a resident refuses a medication or treatment, the physician is promptly notified. Sometimes this standard does not translate into other aspects of care, such as acting on evidence that nutrition practices are not achieving intended outcomes. When a resident refuses a meal food or is observed consuming minimal amounts of food, prompt action is needed. Using current practice standards, physician notification may not occur until the resident loses weight. A proactive approach, which employs the nursing process, for all aspects of care, including nutrition, should be the practice standard. The nursing process, which involves assessment, diagnosis of need, planning of resident's care, implementation, and evaluation of success of implemented care, supports honoring resident preferences and implementing dining practices that support choice.^{131, 132}

Relevant Research Trends

Caregivers often fear that residents' mealtime choices will result in negative outcomes. Mealtime dining studies provide evidence that enabling residents to choose what they want to eat at mealtime does not result in negative nutritional outcomes. Enabling choice can increase nutritional intake and increase resident, family and caregiver satisfaction.^{133, 134, 135, 136} Moreover, these studies demonstrate that usual care, which does not provide for resident choice, when compared to dining practices that enable choice, can result in negative outcomes such as worsening of nutritional markers and quality of life indicators.

Ongoing discussions of where residents are on the health illness/trajectory and modifications of care goals are essential to providing person-directed care. The health care

¹³⁰ American Association of Colleges of Nursing 2008. *The Essentials of Baccalaureate Education for Professional Nursing Practice*. Washington, DC: American Association of Colleges of Nursing.

¹³¹ Remsburg, Robin. *Home-style Dining Interventions in Nursing Homes: Implications for Practice*. Paper for CH II 2010.

¹³² Pioneer Network/Hartford Institute Nurse Competencies for Nursing Home Culture Change <http://www.pioneernetwork.net/Data/Documents/TenCompetenciesReport0510.pdf>.

¹³³ Remsburg, R.E., Luking, A., Baran, P., Radu, C., Pineda, D., Bennett, R.G., Tayback, M. 2001. Impact of a buffet-style dining program on weight and biochemical indicators of nutritional status in nursing home residents: a pilot study. *J Am Diet Assoc*, 101(12), 1460-3.

¹³⁴ Nijis, K.A.N.D., de Graff, C., Siebelink, E., Blauw, Y.H., Vanneste, V., Kok, F.J., van Staveren, W.A. 2006. Effect of family-style meals on energy intake and risk of malnutrition in Dutch nursing home residents: A randomized control trial. *J Gerontol A Biol Sci Med Sci*, 61(9), 935-42.

¹³⁵ Nijis, K.A.N.D., de Graff, C., Kok, F.J., van Staveren, W.A. 2006. Effect of family style mealtimes on quality of life, physical performance, and body weight of nursing home residents: Cluster randomized controlled trial. *BMJ*, 10, 1-5.

¹³⁶ Ruigrok, J. & Sheridan, L. 2006. Life enrichment programme: Enhanced dining experience, a pilot project. *Internat J of Health Care*, 19(5), 420-429.

team needs to recognize when the goal of nutritional care is no longer prevention or restoration, but rather comfort and palliation. Identifying when to shift practices to support palliative nutrition will ensure the resident receives quality care at the end of life. Continuing to provide active restorative nutritional care when it is likely to have limited, if any effect on the well-being of the resident, can create great distress for the resident, family and caregivers.¹³⁷

From researcher psychologists Ellen Langer and Judith Rodin:

I had recently completed research on the illusion of control, which showed me how important it was for people to control their own lives. It was so important that even in chance-determined situations, people would not relinquish their control. Therefore, with the slightest provocation, they engaged in illusory control behavior. Around this same time, I was visiting my grandmother in a nursing home. I was struck by how little control she and the other residents were permitted. I thought this was outrageous. How could 'they' be so sure they know better than these people? I thought all facts were probabilistic statements so their certainty bothered me.

Let me give you an example to make this clearer. Should an elderly diabetic be allowed to have ice cream? The relationship between diabetes and sugar is probabilistic even though it is treated by many people as absolute. Whether or not that ice cream will hurt the person depends on what else was eaten that day, how much ice cream is consumed, whether or not the person has exercised, and so on. Recent evidence, in fact, suggests that no sugar is more dangerous than a small amount of sugar. Regardless of the findings, however, I think nursing-home staff should make recommendations, but leave the final decision up to the resident. One cannot know today what "facts" will turn up tomorrow.

I approached Judy Rodin at Yale, who was also working in the area of control at this time. She too felt that this population was characteristically denied the opportunity to exercise control. Together we visited local nursing homes.... The experiment we conducted was successful. Psychologically, control proved to be a potent variable. The follow-up showed us that control was also important physiologically. Half as many people given our control intervention had died 18 months later than those given a comparison treatment. Because the longevity findings were so dramatic, I've spent a good deal of time trying to understand how such a simple treatment (a pep talk encouraging decision making, a few decisions, and a plan to take care of) could have such a profound effect on people.

¹³⁷ Remsburg, Robin. Home-style Dining Interventions in Nursing Homes: Implications for Practice. Paper for CH II 2010.

The experimental group also showed “a significant improvement over the control group in alertness, active participation, and general sense of well-being.”¹³⁸

Current Thinking

The Eden Alternative® recognizes helplessness as one of the three plagues of institutionalization.

In the institutional setting staff learn that if residents cooperate with their ability to help them, it is a more efficient use of their time. The price paid is for the resident to learn to wait to be helped. This squelches autonomy, skills atrophy, residents become even more dependent on care givers, and have even less control over their lives. Staff’s style of speech encourages learned dependency. Intonation is often similar to what is used with children which causes an adult to feel devalued. Research shows the person loses faith in their ability to affect outcomes in their own world.¹³⁹

Not supporting individualized care and a person’s choice, not supporting “the right to folly,” causes learned helplessness, depression, learned dependency, even bringing death earlier. We have not intended harm with our good intentions, but we are creating it. The Hippocratic Oath is known as “Do no Harm.”¹⁴⁰

It is as difficult as staring straight at the sun, but if we as a profession are to initiate radical change, then we must be conscious of and focus on the harm that we do. Harm – not just to the body, but to the very person – is systematically embedded in bureaucratic institutions that strip elders of their personhood.¹⁴¹

The harm, the potential harm, we overly identify and worry about is to the body. When a person will not follow recommended medical advice, aka the physician’s order, we worry about the physical harm it might cause their body. Notice too how it is called “against medical advice” as if the person is somehow wrong to go against the physician’s advice, again a bad person, “non-compliant.” We haven’t contemplated much the harm to the person that results from denying them this right, the right to go against medical advice, the right to their personhood, their life, their schedule, their wishes. No one should have to fight for, cry for or be told ever again, “You can’t come in the dining room until the doors are open” or “You can’t have this because it’s not on your diet.” We decide for people they will only drink decaf coffee. We decide for people they can only eat this food and not eat that food. If you were denied your rights to this extent, would it feel like abuse, neglect?

¹³⁸ Langer, Ellen J. This Week’s Citation Classic: Sept. 20, 1985. Current Contents/Number 44, November 4, 1985, 14.

¹³⁹ Ronch, Judah 2006 CMS satellite broadcast Psychosocial Severity Outcome Guide www.pioneernetwork.net.

¹⁴⁰ Bowman, The Food and Dining Side of the Culture Change Movement: Identifying Barriers and Potential Solutions to furthering Innovation in Nursing Homes Background paper for CHII 2010.

¹⁴¹ Frank, Barbara, Sarah Forbes-Thompson and Stephen Shields. “The Why and How of Radical Change.” Nursing Homes/Long Term Care Management, May 2004, 44-47.

Part of the culture change movement is to call things as they are and not longer sugar coat.¹⁴²

The Reasonable Person Concept is defined as when a resident's reaction to a deficient practice is markedly incongruent with the level of reaction the reasonable person would have to the deficient practice (CMS).¹⁴³

Even if a resident's reaction is that it is "fine" for her/his choice not to be honored this is "markedly incongruent" with a reasonable person like you and I living in the community at large. If someone gave us decaf coffee when we wanted caffeinated or woke us up according to when they thought we should get up, we would not be happy about it ... to say the least. I ask people all over the country how many of them do not even eat breakfast. Inevitably half the crowd raises their hands whether there are 8 or 800. Half of us do not eat breakfast. What is the number one driving force in every nursing home every day for getting people up? Breakfast. Why do we even wake people up at all? Breakfast. I ask my half a crowd how they would feel about being awakened from sleep to eat a meal they didn't want. They say "mad" and "angry." Someone inevitably says they would be "non-compliant" and administered a psychotropic drug in order to be compliant. Unfortunately, this is the norm, according to my audiences. This is Unnecessary Drugs. This is restraining a person for the convenience of staff, for honoring what a CNA once called the "almighty schedule" not the person. This is non-compliance with the federal requirements. It is the dawning of a new day to realize there are negative outcomes we are not considering and people's health and well-being are in the balance (Ibid).

Develop approaches to dining that reflect a view of elders as capable of making choices and deciding what, when, and with whom to dine as a mental wellness activity because it "exercises" the decision making circuitry of the brain, enhances pleasure, and strengthens memory encoding and retrieval.¹⁴⁴

Residents who receive good personalized care and opportunities for choice have higher morale, greater life satisfaction, and better adjustment (Institute of Medicine).¹⁴⁵

Recommended Course of Practice

All health care practitioners and care giving team members offer choice in every interaction even with persons with cognitive impairment in order to ensure control remains with the person, higher satisfaction with life, improved brain health and to prevent any harm from not honoring choice which has been proven to bring about earlier mortality.

¹⁴² Bowman, Background paper for CHII 2010.

¹⁴³ CMS Psychosocial Severity Outcome Guide, State Operations Manual, Appendix P, 2006.

¹⁴⁴ Ronch, Food for Thought: The Missing Link between Dining and Positive Outcomes paper for CHII 2010.

¹⁴⁵ Improving the Quality of Care in Nursing Homes. Institute of Medicine. Committee on Nursing Home Regulation. National Academy Press; Washington, D.C., 1986.

Patient Rights and Informed Consent/Refusal across the Healthcare Continuum

One of the most thorough resources found on this subject pertaining to any person's rights in any healthcare setting is the following from the 2005 Mayo Clinic Proceedings.

McMahon, MM, Hurley, DL, Kamath, PS, Mueller, PS. Medical and Ethical Aspects of Long-term Enteral Tube Feeding. Mayo Clinic Proc. Nov. 2005; 80(11): 1461-1476
<http://www.mayoclinicproceedings.com/content/80/11/1461.full.pdf>.

FREQUENTLY ENCOUNTERED CLINICAL AND ETHICAL ISSUES

The following case examples illustrate frequently encountered clinical and ethical questions related to long-term tube feeding.

Illustrative Case 1. A 95-year-old woman with mild dementia was hospitalized with progressive neuromuscular disease and dysphagia. She experienced a 10% unintentional weight loss during the prior 3 months and dehydration due to the inability to take food and water by mouth for 1 week. Videofluoroscopic swallow evaluation revealed aspiration of all consistencies of food and liquid. Tube feeding was recommended because permanent tube feeding was anticipated. The patient was alert and oriented to person, place, and time, could articulate the risks, benefits, and alternatives to tube feeding discussed with her, and wished to proceed with percutaneous endoscopic gastrostomy (PEG). After the procedure, she expressed a desire to eat small amounts of food in addition to receiving tube feeding. Again, she could articulate the risks (e.g., aspiration), benefits, and alternatives to eating small amounts of food and remained steadfast in her desire to eat.

--The word autonomy is derived from the Greek words *autos* ("self") and *nomos* ("rule"). The principle of respect for patient autonomy is the basis of informed consent. The elements of informed consent include information (e.g., the illness, the proposed intervention, and the risks and benefits of and alternatives to the proposed intervention including doing nothing), understanding of the information, decision-making capacity, and voluntary agreement to the intervention.

--Society and law assume that all adults are competent.

--Competence is a legal term, and only a court can declare a person incompetent. In contrast, clinicians determine whether a patient has intact medical decision-making capacity, which patients must have to be fully autonomous and participate in the informed consent process. Although no universally accepted tool for determining decision-making capacity exists, numerous groups, including the American Psychiatric Association, provide useful guidelines. Decision-making capacity includes the ability to evidence a choice (i.e., to reach a decision and effectively communicate the decision), the ability to understand the nature of the decision, the ability to understand and appreciate the risks and consequences of the decision, and the ability to manipulate information rationally. Clinicians are obligated to protect patients with impaired decision making capacity from inappropriate

health care decisions. The patient in the case example had mild dementia but had sufficient decision-making capacity for consenting to PEG tube placement and tube feeding. She understood and could articulate the indications, risks, and benefits of the procedure and voluntarily consented to it. Patients with impaired cognition may have sufficient decision-making capacity for specific health care decisions.

ALGORITHM FOR DECISION MAKING

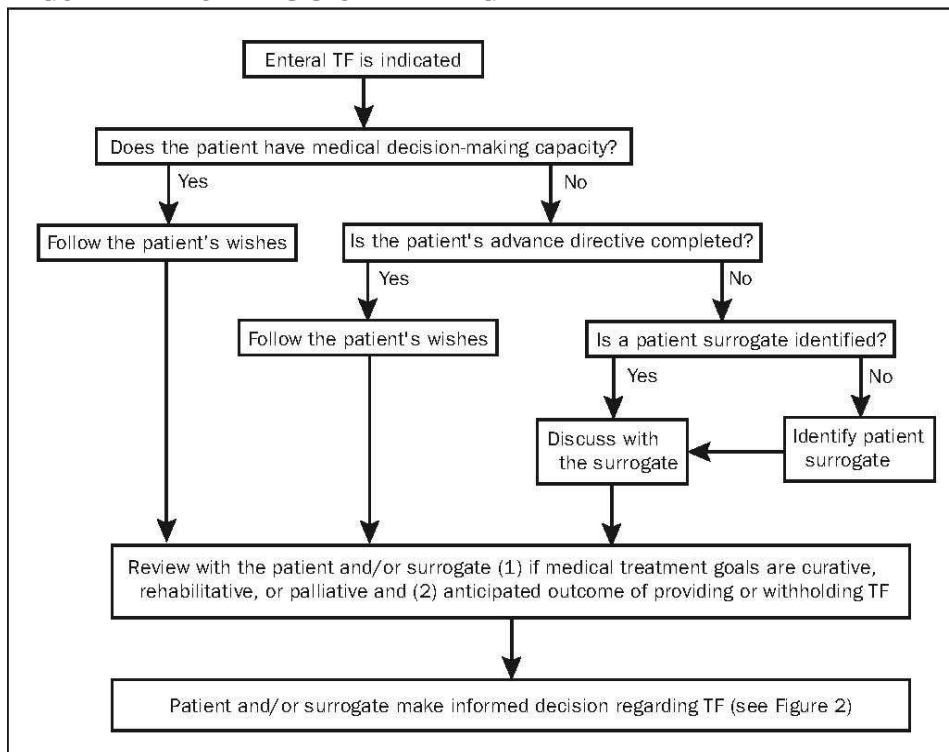


Figure 1. Decision algorithm for long-term tube feeding.

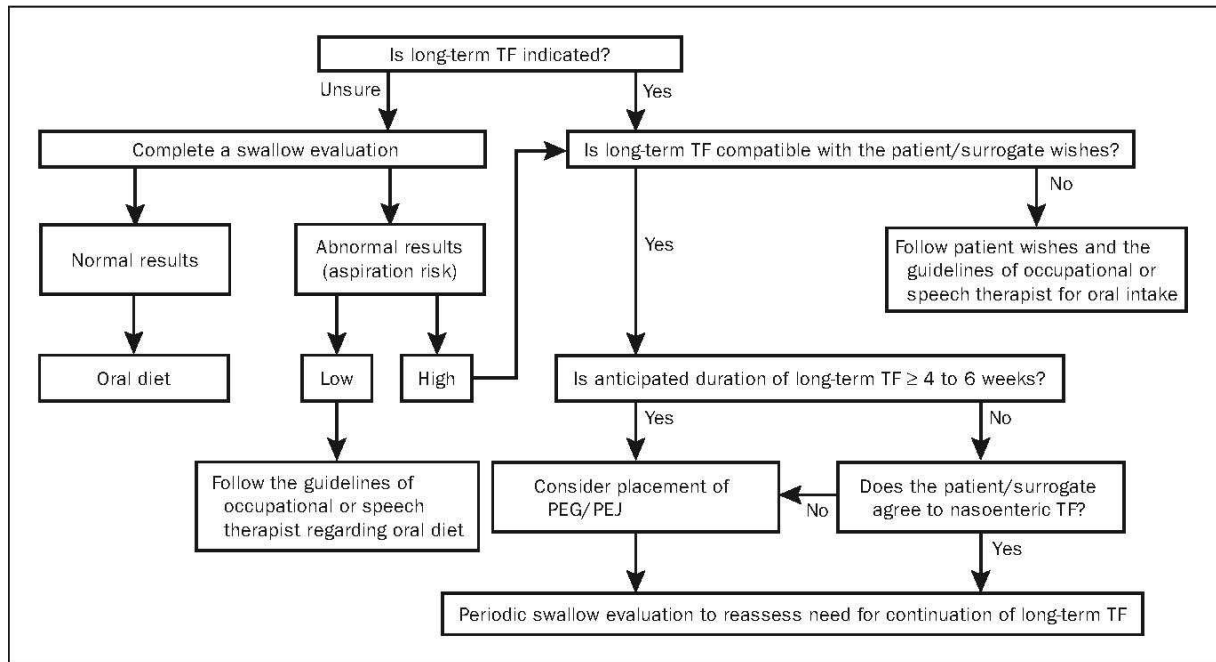


Figure 2. Decision algorithm for long-term enteral tube feeding.

The level of decision-making capacity should be in accordance with the risks and benefits of the decision to be made. For example, one should be absolutely certain that a patient who refuses a low-risk yet life-saving intervention has adequate decision-making capacity. **The patient in the case example expressed a desire to eat small amounts of food despite the risk of aspiration. It is ethically and legally permissible for patients with decision making capacity to refuse unwanted medical interventions and to ignore recommendations of the clinician. A patient’s choice not to adhere to a clinician’s recommendations may be at odds with a clinician’s desire to “do good” or avoid harm. If the patient is sufficiently informed about the risks and benefits of acceptance (informed consent) or refusal (informed refusal) of a proposed intervention or treatment and refuses, the clinician should respect the patient’s decision. In the case example, the patient placed a high value on the experience of tasting even small amounts of food and on the social aspects of eating with others. The Nutrition Support Services discussed potential risks of eating with the patient, documented the discussion, and supported her decision by asking a dietitian and occupational therapist to work with her to develop the safest approach to eating small amounts of food. Regardless of the decisions made, clinicians should not abandon their patients. If the clinician conscientiously objects to a patient’s decision, the clinician should arrange to transfer care of the patient to another clinician.**

---The durable power of attorney for health care identifies a surrogate decision maker who can make health care decisions if the patient no longer has decision-making capacity. Persons also may identify an alternate surrogate in case the first person designated

is unavailable. Some states have a health care directive that combines the features of a living will and durable power of attorney....

Surrogates must be fully informed of the risks, benefits, and alternatives to a proposed procedure or treatment. Surrogates should base their decisions on the patient's previously expressed values and goals (substituted judgment). However, as with the case example, patients often do not discuss their health care values and goals with their surrogate. In these situations, surrogates must make decisions based on what they regard as most appropriate for the patient's clinical condition, quality of life, and other factors (best interest of the patient). Notably, patients may regard designating a trusted surrogate as more important than trying to predetermine all the possible future medical issues and circumstances that may require a decision.

PREVENTING AND ADDRESSING ETHICAL DILEMMAS

The prima facie principles that characterize the ethical aspects of clinical medicine are respect for patient autonomy, beneficence, nonmaleficence, and justice.

-- Respect for patient autonomy refers to the duty to respect persons and their rights of self-determination.

--Beneficence refers to the clinician's duty to act for the good of the patient, whereas nonmaleficence refers to the duty to avoid harming the patient.

--Justice refers to the duty to treat patients fairly.

When caring for patients for whom long-term tube feeding is being considered, clinicians may find these ethical principles at odds with each other. For example, respect for patient autonomy may conflict with the clinician's desires to be beneficent and to avoid harm. Effective communication among clinicians, patients, and surrogate decision makers may help prevent ethical dilemmas. Clinicians should take time to learn about the patient and the patient's values, goals, and beliefs. The patient should be provided ample time to discuss and provide his or her concerns related to nutrition and hydration. When conveying medical information concerning benefits and risks of long-term tube feeding, clinicians should avoid using complex medical language and frequently should assess the patient's comprehension. Conversely, ineffective communication among clinicians, patients, and surrogate decision makers may result in ethical dilemmas. Lack of training, perceived lack of time, fear of the patient's emotional response, and general discomfort with these topics may result in clinicians avoiding these discussions. In fact, discussions about life-sustaining treatments between clinicians and patients are reportedly uncommon.

Despite good communication, clinicians may face ethical dilemmas related to long-term tube feeding that they cannot resolve. In these situations, an ethics consultation may be valuable. The Ethics Consultation Service at our institution uses the 4-topic case-based approach described by Jonsen et al. This approach (below) reviews medical indications, patient preferences, quality of life, and contextual (e.g., financial, religious, cultural, and allocation of resources) issues of a given case and facilitates the exposition, organization, and analysis of the ethically relevant facts (i.e., the facts related to the prima facie ethical principles). Answering the questions is a convenient approach to the 4 topics, and,

reviewed together, the answers to the questions not only define the ethical problem but often suggest a solution.

CONCLUSIONS

The use of long-term tube feeding has increased substantially. Review of the literature highlights the need for improved education for physicians, patients, and surrogate decision makers about use of long-term tube feeding and its ethical implications. Clinicians should take an active role in recommending advanced directives to their patients. Patients should be encouraged to identify a surrogate decision maker and to make intentions clear to this person about use of long-term tube feeding. Although outcome data from prospective, randomized, controlled studies are limited, information from observational studies is useful. In general, PEG or percutaneous endoscopic jejunostomy (PEJ) feeding tube placement should not be considered unless the anticipated duration of tube feeding is at least 1 month. The technical procedures to secure enteral tube access are generally safe, but they are not risk free. A simple guideline to outline the appropriate use of long-term tube feeding does not exist because each person has a unique perspective about their quality of life. As with other forms of medical interventions and treatments, the approach should be individualized. However, as discussed earlier, a systematic approach (Figures 1 and 2) can facilitate the decision-making process.

Physicians [and the interdisciplinary team] should first determine whether the patient's treatment goals are potentially curative, rehabilitative, or palliative. Next, to allow informed decision making, clinicians should clearly communicate with patients and surrogate decision makers about the patient's diagnosis, prognosis, and potential outcomes from providing or withholding long-term tube feeding. For patients in the terminal stages of dementia, cancer, or other illnesses, current studies do not document improved outcome from long-term tube feeding use. It is unrealistic to expect artificial nutrition to favorably improve medical outcomes in these conditions; however, it is important to recognize that, in certain situations, patients and surrogate decision makers will choose long-term tube feeding to achieve personal goals, independent of medical outcome. If the potential medical outcome is curative or rehabilitative, the decision should rest on the patient's wishes. Patients and surrogate decision makers should be given sufficient time and support for making informed decisions regarding long-term tube feeding use, and their decisions should be honored. Research is needed to improve the clinician's ability to estimate the needed duration of artificial nutrition in order to select short-term vs. long-term enteral access for feeding and to assess the effect of long-term tube feeding on quality of life and medical outcome for differing medical conditions.

Four-Topic Approach to Identify Ethically Relevant Facts

[The PEG/PEJ placement and long-term tube feeding is underlined indicating that any course of treatment could be inserted into this four-topic approach to decision making.]

Medical indications

The principles of beneficence and nonmaleficence

1. What is the patient's medical problem that is prompting consideration of PEG/PEJ placement and long-term tube feeding? Prognosis?
2. Is the problem acute? Chronic? Critical? Emergent? Reversible?
3. What are the goals of PEG/PEJ placement and long-term tube feeding?
4. What are the probabilities of success?
5. What are the plans in case of therapeutic failure?
6. In sum, how can this patient benefit from medical and nursing care, and how can harm be avoided?

Patient preferences

The principle of respect for patient autonomy

1. Does the patient have decision-making capacity?
2. If the patient has decision-making capacity, what are his or her preferences for treatment?
3. Has the patient been informed of the benefits and risks of PEG/PEJ placement and long-term tube feeding, understood this information, and given consent?
4. If the patient lacks decision-making capacity, who is the appropriate surrogate?
5. Has the patient expressed preferences about PEG/PEJ placement and long-term tube feeding previously (e.g., advance directive)?
6. Is the patient unwilling or unable to cooperate with treatment? If so, why?
7. In sum, is the patient's right to choose being respected to the extent possible in ethics and law?

Quality of life

The principles of beneficence, nonmaleficence, and respect for patient autonomy

1. What are the prospects, with or without PEG/PEJ placement and long-term tube feeding, for a return to normal life?
2. What physical, mental, and social deficits is the patient likely to experience if treatment succeeds?
3. Are there biases that might prejudice the clinician's evaluation of the patient's quality of life?
4. Is the patient's present or future condition such that his or her continued life might be judged undesirable?
5. Is there any plan and rationale to forgo treatment?
6. Are there plans for comfort and palliative care?

Contextual features

The principles of loyalty and fairness (justice)

1. Are there family issues that may influence decisions related to PEG/PEJ placement and long-term tube feeding?
2. Are there clinician issues that may influence treatment decisions?
3. Are there financial and economic factors?
4. Are there religious or cultural factors?
5. Are there limits on confidentiality?
6. Are there problems of allocation of resources?
7. How does the law affect treatment decisions for PEG/PEJ placement and long-term tube feeding?
8. Is clinical research or teaching involved?
9. Is there any conflict of interest on the part of clinicians or the institution?

Adapted from Jonsen et al, 111 with permission from McGraw-Hill.

Jonsen AR, Siegler M, Winslade WJ. Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine. 5th ed. New York, NY: McGraw Hill; 2002.

(Permission to use has been requested from Mayo Clinic Proceedings as of 1/31/11.)

References

AMDA – www.amda.com

- AMDA Synopsis of Federal Regulations in the Nursing Home: Implication for Attending Physicians and Medical Directors 2009. Available for a fee.
- AMDA Clinical Practice Guideline: Altered Nutritional Status. 2009. Available for a fee.
- AMDA Clinical Practice Guideline: Diabetes Management in the Long-Term Care Setting 2008. Available for a fee.
- AMDA: The Role of the Medical Director in Person Directed Care, 2010
<http://www.amda.com/governance/whitepapers/G10.cfm>

ADA – www.eatright.org/HealthProfessionals

- ADA Position Paper Individualized Nutrition Approaches for Older Adults in Health Care Communities 2010.
- ADA Position Paper Liberalization of the Diet Prescription Improves Quality of Life for Older Adults in Long-Term Care 2005.
- ADA Evidence Analysis Library. ADA Unintended Weight Loss Nutrition Practice Guideline 2009.
- Roberts, L, Cryst Suzanne C, Robinson, G, Elliott, C, Moore L C, Rybicki M, Carlson, M. American Dietetic Association: Standards of Practice and Standards of Professional Performance for Registered Dietitians (Competent, Proficient and Expert) in Extended Care Settings. *J Am Diet Assoc.* 2011; 111:617-624; 624.e1-e27.
www.eatright.org/HealthProfessionals/content.aspx?id=6867

DMA – www.DMAonline.org

- DMA Position Paper The Role of the Certified Dietary Manager in Person-Directed Dining 2011. *Handy, Linda, Dietary Manager's Association: "The Role of the Certified Dietary Manager in Person-Directed Dining," DMA Magazine, April 2011, page 13.*
http://www.DMAonline.org/Members/Articles/2011_04_positionPaper.pdf
- *Handy, Linda, Dietary Manager's Association: "Your Role in Ensuring Culture Change in Dining and Regulatory Compliance," DMA Magazine, June 2010, page 14.*
http://www.DMAonline.org/Members/Articles/2010_06_cultureChange.pdf

CMS – www.cms.gov

- Psychosocial Severity Outcome Guide, State Operations Manual, Appendix P, 2006.
- State Operations Manual for LTC Facilities Appendix PP 1/2011 update

Pioneer Network – www.pioneernetwork.net

- *Nurse Competencies for Nursing Home Culture Change, May 27, 2010.* Pioneer Network/Hartford Institute for Geriatric Nursing.

- The following papers and accompanying webinars can be accessed at www.pioneernetwork.net >>Conferences>>Creating Home II: Food and Dining. This National Symposium on Culture Change and the Food and Dining Requirements were sponsored by CMS and Pioneer Network, February 2010:

Bump, Linda. The Deep Seated Issue of Choice.

Leible, Karyn and Wayne, Matthew. The Role of the Physician's Order.

Handy, Linda. Survey Interpretation of Regulations.

Hyde, Denise. The Role of the Pharmacist.

Remsburg, Robin. Home-style Dining Interventions in Nursing Homes: Implications for Practice.

Ronch, Judah. Food for Thought: The Missing Link between Dining and Positive Outcomes.

Simmons, Sandra F., Bertrand, Rosanna M. Enhancing the Quality of Nursing Home Dining Assistance: New Regulations and Practice Implications.

Bowman, Carmen. The Food and Dining Side of the Culture Change Movement: Identifying Barriers and Potential Solutions to furthering Innovation in Nursing Homes Background Paper for the Feb. 2010 CHII. Report of CMS Contract HHSM-500-2009-00057P.

- The following papers some of which address the dining environment, were written for the Creating Home (I) Creating Home in the Nursing Home: A National Symposium on Culture Change and the Environment Requirements sponsored by CMS and the Pioneer Network, April 2008:

Calkins, Margaret. Private vs. Shared Bedrooms in Nursing Homes.

Nelson, Gaius. Household Models for Nursing Home Environment

Brawley, Elizabeth. Lighting: Partner in Quality Care Environments.

Cutler, Lois. Nothing is Traditional about Environments in Traditional Nursing Homes.

Calkins, Margaret. Creating Home in the Nursing Home: Fantasy or Reality?

Bowman, Carmen. The Environmental Side of the Culture Change Movement: Identifying Barriers and Potential Solutions to furthering Innovation in Nursing Homes. Background Paper to the April 3rd, 2008 Creating Home in the Nursing Home: A National Symposium on Culture Change and the Environment Requirements. Report of CMS Contract HHSM-500-2005-00076P.

Free Water Protocols

Panther, K. (2005). The Frazier Free Water Protocol. Perspectives on Swallowing and Swallowing Disorders (Dysphagia), 14 (1), 4-9.

Planetree Long Term Care Improvement Guide

<http://www.planetree.org/LTC%20Improvement%20Guide%20For%20Download.pdf>