End of Life Nutrition and Hydration

Comprehensive Nutrition Assessment and Interventions for Older Adults

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End of Life Nutrition and Hydration

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End of Life Nutrition and Hydration

Table of Contents

Chapter 1: Nutrition Assessment at the End of Life ................................................................. 1
  ♦ Introduction .......................................................................................................................... 1
  ♦ Advanced Directives Regarding Nutrition and Hydration .................................................. 1
  ♦ End of Life Care Planning ..................................................................................................... 2
  ♦ The Role of the Registered Dietitian Nutritionist (RDN) .................................................... 3
  ♦ End of Life Medical Nutrition Therapy ............................................................................... 3
  ♦ Nutrition Screening ............................................................................................................ 3
  ♦ Nutrition Care Process ....................................................................................................... 4
  ♦ Nutrition Assessment ......................................................................................................... 4
  ♦ Nutrition Focused Physical Examination .......................................................................... 5
  ♦ Laboratory Assessment .................................................................................................... 5
    - Evaluating Protein Status ................................................................................................. 5
    - Dehydration .................................................................................................................... 6
    - Risk Factors for Dehydration .......................................................................................... 6
    - Fluid and Electrolyte Volume Deficit Disorders ............................................................ 6
    - Anemia ............................................................................................................................ 7
  ♦ Malnutrition ....................................................................................................................... 8
    - Introduction ..................................................................................................................... 8
    - Consequences of Malnutrition ....................................................................................... 8
    - Diagnosing Malnutrition ................................................................................................. 8
    - Proposed Clinical Characteristics Used to Categorize Malnutrition ............................... 9
  ♦ Estimating Nutritional Needs ............................................................................................. 9
    - Energy Needs ................................................................................................................ 9
    - Mifflin-St. Jeor Equation ................................................................................................. 11
    - Alternate Methods of Calculating Energy Needs ............................................................. 11
    - Estimating Protein Needs ............................................................................................... 11
    - Estimating Fluid Needs .................................................................................................. 13
    - General Guidelines for Estimating Fluid Needs ............................................................ 13
    - Preferred Method of Estimating Fluid Needs for Obese Individuals ............................... 13
    - Alternate Methods of Calculating Fluid Needs (mL/day) ................................................ 13
    - Factors That May Increase Fluid Needs ......................................................................... 13
    - Factors That May Require Decreased Fluid Intake ....................................................... 13
    - Signs of Over-hydration ................................................................................................. 13
  ♦ The MDS 3.0 and Care Plan ............................................................................................... 14
  ♦ References for Chapter 1: Nutrition Assessment at the End of Life ................................. 14

Chapter 2: Determining Nutrition Care Plan at the End of Life ............................................. 17
  ♦ Considerations for Determining a Nutrition Care Plan at the End of Life ...................... 17
  ♦ Benefits and Risks of Enteral Nutrition .......................................................................... 18
    - Medical Conditions/Treatments That May Indicate the Need for Enteral Nutrition .... 18
    - Medical Contraindications of Enteral Feeding ............................................................... 18
  ♦ Potential Risks of Enteral Nutrition ............................................................................... 19
  ♦ Tube Feeding and Aspiration ............................................................................................ 19
  ♦ Enteral Nutrition Near the End of Life ............................................................................ 20
  ♦ Tube Feeding and Dementia ............................................................................................. 20
  ♦ Considerations for Health Care Professionals ................................................................. 20
  ♦ References for Chapter 2: Determining Nutrition Care Plan at the End of Life ............. 21
End of Life Nutrition and Hydration

Chapter 3: Comfort-Guided Care

♦ Resources for End of Life Decisions ........................ .......................................................... 22

♦ Chapter 3: Comfort-Guided Care .......................................................... 23
  ♦ Choosing Comfort-Guided Nutrition Care .......................................................... 23
    - Comfort-Guided Care and Wound Management .............................................. 23
    - Comfort-Guided Care and Appetite Enhancing Medications ...................... 23
  ♦ Palliative Care and Hospice Care .......................................................... 24
  ♦ End of Life Symptoms that May Affect Nutritional Care .................................. 24
  ♦ End-of-Life Pain and Discomfort Related to Food and Fluid Intake .................. 28
  ♦ Meeting State and Federal Regulations at End of Life ...................................... 28
  ♦ Legal Issues and End of Life Care .......................................................... 28
  ♦ References for Chapter 3: Comfort-Guided Care ............................................ 29

Chapter 4: Enteral Nutrition at the End of Life

♦ Resources for Chapter 4: Enteral Nutrition at the End of Life .......................... 30

♦ Chapter 4: Enteral Nutrition at the End of Life ........................................... 30
  ♦ Implementing Tube Feeding .......................................................... 30
  ♦ Selecting Type of Feeding Tube .......................................................... 30
  ♦ Nutrition Care of the Tube-Fed Individual .................................................. 30
  ♦ Implementing Enteral Nutrition .......................................................... 32
  ♦ Selecting Enteral Formulas .......................................................... 32
    - Considerations for Choosing a Disease-Specific Enteral Formula ............... 33
    - Blenderized Tube Feedings .......................................................... 35
  ♦ Selecting a Delivery Method .......................................................... 35
    - Types of Enteral Feeding Administration ................................................. 35
  ♦ Determining a Tube Feeding Schedule ................................................... 36
    - Example .................................................................................. 37
    - Calculations for Total Volume of Enteral Feeding ...................................... 37
    - Calculations for Administration of Feeding .............................................. 37
  ♦ Determining Volume of Feeding Needed to Meet Estimated Protein/Calorie Needs .................................................. 38
    - Calculating Calories Provided by an Enteral Feeding .............................. 38
    - Calculating Protein Provided by an Enteral Feeding .................................. 38
    - Calculating Flushes for Enteral Feedings ............................................... 39
  ♦ Using Feeding Tubes to Deliver Medications ............................................. 39
  ♦ Drug-Nutrient Interactions .......................................................... 39
  ♦ Complications of Enteral Feeding ......................................................... 40
    - Diarrhea .................................................................................. 40
    - Aspiration .................................................................................. 40
    - Clogged Tube ........................................................................... 41
    - Constipation ............................................................................. 41
    - Abdominal Distention .................................................................. 41
    - Nausea/Vomiting ....................................................................... 41
    - Fluid and Electrolyte Imbalance ...................................................... 42
    - Contamination of Formula ........................................................ 42
  ♦ Monitoring for Refeeding Syndrome ....................................................... 42
    - Refeeding Syndrome .................................................................. 42
  ♦ Meeting State and Federal Regulations for Tube Feeding .............................. 43
  ♦ Transitioning from Enteral Feeding to Oral Feeding ..................................... 44
  ♦ Discontinuing Enteral Feeding at the End of Life .......................................... 45
  ♦ References for Chapter 4: Enteral Nutrition at the End of Life .................... 46
  ♦ Resources ..................................................................................... 47

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### Chapter 5: Policies and Procedures

- Medical Nutrition Therapy Recommendations .................................................. 48
  - Nutrition Recommendations Sample Form ...................................................... 49
- Communication of Nutritional Concerns .............................................................. 50
- Nutrition Screening for Referrals to Registered Dietitian Nutritionist ......................... 51
- Referrals to the Registered Dietitian Nutritionist .................................................. 53
  - Referrals to the Registered Dietitian Nutritionist Sample Form [1] ......................... 54
  - Referrals to the Registered Dietitian Nutritionist Sample Form [2] ......................... 55
- Medical Nutrition Therapy Documentation ......................................................... 56
  - Resource: Role Delineation (Division of Responsibility for Documentation) .............. 58
- Comprehensive Medical Nutrition Therapy Assessment ......................................... 60
  - Resource: Medical Nutrition Therapy Assessment: Components of a Comprehensive Assessment .................................................. 63
  - Resource: PES Statements Sample .................................................................... 66
- Comprehensive Care Plan ...................................................................................... 68
  - Resource: Weight Related Nutrition Interventions ................................................. 70
- Tracking Weight Changes ....................................................................................... 73
  - Monthly Weight Record Sample Form .................................................................. 74
  - Individual Weight Chart Sample Form .................................................................. 75
  - Weekly Weight Record Sample Form .................................................................... 76
  - Significant Weight Changes Sample Form ........................................................... 77
  - Significant Weight Loss Sample Form ................................................................... 78
  - Weight Change Notifications and Recommendations Sample Form ....................... 79
  - Significant Weight Loss Communications Sample Form ........................................ 80
- Significant Weight Loss ......................................................................................... 81
- Interventions for Unintended Weight Loss ............................................................. 84
- Immediate Temporary Interventions for Unplanned Significant Weight Loss .................. 85
- Nutrient Intake Study ............................................................................................ 86
  - Food Intake Study Sample Form .......................................................................... 87
  - Resource: Potential Interventions for Unintended Weight Loss ......................... 88
- Dehydration ............................................................................................................ 90
  - Resource: Additional Recommendations for Promoting Adequate Hydration ............ 92
- Dysphagia ............................................................................................................... 93
  - Warning Signs of Dysphagia ............................................................................... 94
  - Resource: Positioning Tips to Increase Independence and Reduce Risk of Aspiration or Choking .......................................................... 95
- Thickened Liquids .................................................................................................. 96
- End of Life Decisions ............................................................................................. 98
- Guidelines for Enteral Feeding Eligibility ............................................................... 99
- Enteral Nutrition Care ............................................................................................ 100
- Basic Guidelines for Enteral Feeding ...................................................................... 101
- Documentation for Enteral Feeding ........................................................................ 102
- Enteral Feeding Assessment ................................................................................... 103
- Transitioning from Enteral Feedings to Oral Feedings ............................................. 104
- Documenting in the Medical Record ....................................................................... 105

### Chapter 6: Regulatory Information

- State Operations Manual Appendix PP – Guidance to Surveyors for Long Term Care (Revision 157, 6-10-16): 483.25 Naso-Gastric Tubes .................................................. 108
End of Life Nutrition and Hydration

- Hospice/End of Life and/or Palliative Care Critical Element Pathway (CMD 20073) ............................................. 120
- CMS Tube Feeding Status Critical Element Pathway (CMS 20093) ................................................................. 138
- CMS RAI Manual MDS Section K ....................................................................................................................... 162
- CMS RAI Manual, Ch 4: CAA Process and Care Planning: Nutritional Status, Feeding Tubes and Dehydration/Fluid Maintenance ................................................................. 179
- CMS State Operations Manual Appendix PP – Guidance to Surveyors for Long Term Care (Revision 157, 6-10-16): 483.10 Right to refuse treatment ......................................................... 183
- Sources for Regulatory Information ................................................................................................................... 200

Chapter 7: Patient and Family/Surrogate Education ................................................................................................. 201
- Choosing Comfort-Guided Nutrition Care: Frequently Asked Questions ......................................................... 202
- End of Life Symptoms that Affect Nutritional Care .............................................................................................. 203
- Managing Gastro Intestinal (GI) Symptoms ........................................................................................................ 206
- Helpful Hints for Nausea or Vomiting .................................................................................................................. 208
- Helpful Hints for Cramps, Heartburn, and Bloating ............................................................................................ 209
- Helpful Hints for Diarrhea ................................................................................................................................... 210
- Dehydration: Risk Factors and Symptoms ........................................................................................................ 211
- Estimating How Much Fluid you Need Daily ........................................................................................................ 212
- All About Dysphagia ............................................................................................................................................. 213
- Positioning Tips for Those with Swallowing Problems ....................................................................................... 214
- Preparing Pureed Food ........................................................................................................................................ 215
  - Tips for Safe Preparation of Pureed Foods ........................................................................................................ 215
- Basic Recipes and Tips for Preparing Pureed Foods .......................................................................................... 215
  - Pureed Vegetables ............................................................................................................................................ 215
  - Pureed Meat ..................................................................................................................................................... 216
  - Pureed Fruit ...................................................................................................................................................... 217
  - Pureed Casserole .............................................................................................................................................. 217
- Thickened Liquids ................................................................................................................................................ 218
- Weight Loss in the Elderly .................................................................................................................................. 219
- Boosting Nutritional Value with Fortified Foods .............................................................................................. 220
  - Calorie Boosters .............................................................................................................................................. 220
  - Protein Boosters ............................................................................................................................................ 221
- Fortified Food Recipes ........................................................................................................................................ 222
  - Fortified Oatmeal ............................................................................................................................................. 222
  - Orange Creamsicle .......................................................................................................................................... 222
  - Calorie Dense Pudding .................................................................................................................................. 223
  - Ice Cream Delight .......................................................................................................................................... 223
  - Super Soup ....................................................................................................................................................... 223
  - Power Potatoes .............................................................................................................................................. 224
  - Cherry Vanilla Drink ...................................................................................................................................... 224
  - Key Lime Shake .............................................................................................................................................. 225
  - Orange Ale ..................................................................................................................................................... 225
  - Strawberry-Banana Frost ................................................................................................................................ 226
  - Chocolate Dream .......................................................................................................................................... 226
  - Strawberry Frost ........................................................................................................................................... 227
  - Peach Cooler ................................................................................................................................................ 227
- Sample Snack Schedules .................................................................................................................................... 228
- Regular Diet: Sample Enhanced/Fortified Food Schedule .................................................................................. 228
- Nutritional Supplements ...................................................................................................................................... 228
End of Life Nutrition and Hydration

- Risks and Benefits of Tube Feeding Frequently Asked Questions ....................................................... 229

Note: The Patient and Family/Surrogate Educational Materials above are available on the enclosed CD for hard copy purchases. For e-book purchases, these can be downloaded from the link provided on your original order confirmation.

Appendix .................................................................................................................................................. 231
- Medical Nutrition Therapy Assessment Sample Form ................................................................. 232
- Nutrition Care Process Sample Form (page 2 MNT Assessment) .................................................... 233
- MNT Care Plan for Hospice/Palliative/Comfort Care Sample Form .............................................. 234
- Penn State Equation for Predicting Metabolic Rate ........................................................................... 235
- Ireton-Jones Equation for Calculating Energy Needs ............................................................................ 235
  - Spontaneously Breathing Individuals .................................................................................................. 235
  - Ventilator Dependent Individuals ...................................................................................................... 235
- Swinamer Equation .............................................................................................................................. 235
- Alternate Methods of Calculating Energy Needs .................................................................................. 235
- Physical Changes Indicating Altered Nutritional Status ................................................................. 236
- Nutrition Focused Physical Assessment ............................................................................................ 237
  - Performing a Nutrition-Focused Physical Assessment ................................................................. 237
  - Nutrition Focused Physical Assessment and Scope of Practice ...................................................... 237
- Systems Approach to Evaluating Physical Factors for Nutrition Focused Physical Assessment .... 238
- Indicators of Dehydration/Fluid Maintenance ...................................................................................... 239
- Laboratory Tests and Nutrition Interventions Related to Anemia ..................................................... 240
- Nutrition Interventions to Address Malnutrition ................................................................................ 241
- Nutritional Needs During Periods of Stress ......................................................................................... 242
  - General Reactions to Stress Hypermetabolism .............................................................................. 242
  - Metabolic Response to Trauma ........................................................................................................ 242
  - Acute and Adaptive Responses to Trauma ....................................................................................... 243
- Significant Weight Loss Protocol Algorithm ....................................................................................... 244
- How to Talk to Family About Tube Feeding a Patient Without a Terminal Diagnosis Sample ...... 245
- How to Talk to a Family about the Possibility of Inserting a Feeding Tube in a Patient with a Terminal Diagnosis Sample ........................................................................................................... 246
- Decline of Life-Prolonging Procedures and Treatments Sample Form .............................................. 247
- References and Sources for Appendix ............................................................................................... 248

Continuing Professional Education ...................................................................................................... 250
- Instructions for Obtaining Continuing Professional Education ....................................................... 250
- Description .......................................................................................................................................... 250
- Objectives/CDR Level .......................................................................................................................... 251
- CDR Learning Needs Codes and Performance Quality Indicators .................................................... 252
- Continuing Education Professional Expert Reviewers ..................................................................... 253

Note: The following inservices are available on the enclosed CD for hard copy purchases and can be downloaded for e-book purchase from the link provided on your original order confirmation.
- Comfort-Guided Nutrition Care Inservice
- Tube Feed or Not Tube Feed? Inservice
- End of Life Hydration and Hydration Inservice
End of Life Nutrition and Hydration

Chapter 1: Nutrition Assessment at the End of Life

Introduction
When an individual has a serious illness and is unable to consume enough food and fluid, the health care team and patient or their surrogate must begin to consider ways to maintain nutritional status. An individual’s goals of care (palliative, curative, or restorative) play into nutrition care-planning decisions.

At the end of life, anorexia or decreased appetite, difficulty swallowing, or other conditions can interfere with eating and digestion and/or absorption of food and nutrients, resulting in altered nutritional status. If indicated and desired, artificial nutrition and hydration (ANH), also known as enteral nutrition (EN), or more commonly known as tube feeding can be provided. A thin, flexible tube is inserted directly into the stomach, bypassing the mouth and esophagus. EN is preferred over parenteral nutrition (infusion of nutrition through the vein) when the gastrointestinal (GI) tract is healthy because it helps to stimulate or maintain gut function, causes fewer complications, and is the least invasive and least expensive route for providing ANH (1).

Making the choice as to whether or not to initiate tube feeding, particularly near the end of life, can be difficult and emotional. This manual will outline options for end-of-life care, including comfort-guided nutrition care (often referred to as palliative care). It will discuss the risk and benefits of enteral nutrition at the end of life, and provide practical information on the initiation and monitoring of tube feeding if it is desired. The Policies and Procedures, Regulatory Information, and Appendix provide supporting materials.

Individuals that are nearing the end of life will require a nutrition plan of care that is based on nutrition screening and assessment, input from the patient and their family or surrogate, and input from the facility interdisciplinary team (IDT). Goals of care (palliative, curative, or restorative) should be outlined and used to help determine the plan of care. Decisions about the initiation, continuation, or discontinuation of ANH should be made the same way other health care decisions are made by evaluating the risk and potential benefits, goals of treatment, and patient preferences (2).

Advance Directives Regarding Nutrition and Hydration
The Patient Self-Determination Act, a federal law enacted in 1991, requires that individuals be informed about their right to participate in health care decisions, including their right to have an advance directive. Individuals must not only be informed of nutrition options, but deemed competent to make decisions. A competent individual is defined as someone who is informed and able to make their own healthcare decisions. If a person is considered competent, he or she may change or cancel advance directives at any time. A surrogate is someone who is an authorized proxy that will act in the resident’s/patient’s place if that individual loses the ability to make their own decisions about healthcare. If the individual is not able to participate in decision-making, their advance directive, if one exists, can help guide the IDT.

There are two main types of advance directives, living wills and durable powers of attorney. They are both legal documents that allow individuals to convey their decisions about end of life care to family, friends and health care professionals. Unfortunately, some documents, such as a Do Not Resuscitate (DNR) don’t specify whether interventions such as tube feeding or IV fluids are desired. A living will stipulates the type of care the individual desires to sustain life, including tube feedings; while a durable power of attorney identifies the individual’s surrogate or proxy,
End of Life Nutrition and Hydration

who will make health care decisions when the individual is not capable of making their own decisions.

The gold standard for advance care planning would be that an individual and family or surrogate hold thoughtful conversations about end of life decisions, provide detailed documentation of a person’s wishes, and have a well-informed surrogate decision-maker (3). However, many individuals have not addressed and/or documented their end of life wishes. Studies show that about 4 in 10 Americans age 65 and older do not have advance directives or have not written down their goals for end of life medical treatment (4).

In January 2016, the Centers for Medicare and Medicaid Services (CMS) implemented a new rule that allows Medicare to cover advance care planning discussions between health care professionals (physician and nurse practitioners) and patients (5). Conversations can be held in medical offices or facility settings. Two new current procedural terminology (CPT) codes, 99497 and 99498, have been developed to allow billing for initial and follow-up advance planning conversations (6).

Healthcare facilities usually request advance directives upon admission so that the individual, their surrogate, and the IDT all understand the individual’s desires in end of life situations. Advance directives should be reassessed when a significant decline in condition occurs. A Sample Advance Directive can be found in the Appendix of this manual. Advanced directive forms for each state can be downloaded at: http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289.

End of Life Care Planning

When a decline in status is observed, the plan of care will usually change for a patient/resident. More information on care planning can be found in Chapters 5 and 6, and the Appendix. The following guidelines can help provide clarity to the IDT for developing a plan of care.

- The IDT should initiate an accurate and complete assessment (including nutrition assessment by the RDN or designee), review the medical record, and determine if the care plan was implemented correctly and appropriately by qualified staff. Interventions should be evaluated. The plan of care should be changed based on the desires of the individual.
- End of life decisions should be initiated only after the IDT is confident that all other medical and nutritional interventions have been presented and/or implemented.
- The medical record should contain the individual’s advance directive documents such as the Living Will and/or Durable Power of Healthcare/Medical Attorney to indicate the individual’s end of life desires. These documents should be revisited with the patient and/or representative to assure they are still appropriate.
- If no advance directives regarding artificial nutrition and hydration are on file, and it appears necessary to initiate such interventions to sustain life, a member of the IDT should consult with the patient/resident and/or surrogate to determine the individual’s desires. In some facilities one individual (such as the physician, registered dietitian nutritionist, or nurse manager) might be designated to have these sensitive conversations. Facility protocols should be in place so that a patient/family/surrogate is not approached repeatedly.
End of Life Nutrition and Hydration

- The individual’s choices for end of life care should be documented in the medical record. Advanced directive forms for each state can be downloaded at http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289.
- If the patient and/or surrogate are in agreement that aggressive measures are not indicated, the physician should write an order for “comfort measures only” or “palliative care” (depending on facility protocols) and orders followed based on the facility’s definitions of comfort or palliative care. Referral to hospice care may be initiated, if appropriate and desired. Facility staff should honor the individual’s wishes and provide care delivery as determined via the physician’s order.
- If artificial nutrition and/or hydration is desired, orders should be written and the plan of care carried out as outlined in the upcoming pages of this document.
- The care plan should be updated as needed to reflect the end of life decisions made by the individual or the individual’s surrogate. Interventions as described in the plan of care should be implemented and revised as necessary to reflect the individual's needs and choices to provide the highest quality of life possible.

The Role of the Registered Dietitian Nutritionist (RDN)
The RDN plays a significant role on the interdisciplinary team (IDT) including serving as an advocate for the patient and providing medical nutrition therapy (MNT) to meet the individual’s changing goals for care. The RDN can also play an integral role in ethical deliberations with the IDT and/or an individual regarding end of life nutrition care (7). A variety of skills are necessary to help facilitate these conversations, including clinical skills, negotiation skills, and ability to provide understanding and empathy. The RDN can also play a role in establishing facility ethics policies, participating in ethics committees, and educating patients, families, and health care professionals on the risks and benefits of tube feeding at the end of life. The Academy of Nutrition and Dietetics (Academy) Practice Paper titled “Ethical and Legal Issues in Feeding and Hydration” is a valuable tool for RDNs and can be accessed by Academy members at http://www.eatrightpro.org/resource/practice/position-and-practice-papers/practice-papers/practice-paper-ethical-and-legal-issues-in-feeding-and-hydration.

End of Life Medical Nutrition Therapy
Regardless of the nutrition care plan, nutrition screening and the Academy’s Nutrition Care Process should be implemented with changes made as needed to assure goals of care are met.

Nutrition Screening
Each health care facility or agency should have a solid nutrition screening policy in place to identify level of risk for undernutrition or malnutrition and to make appropriate referrals to the registered dietitian nutritionist (RDN). The nutrition screening process should focus on identifying risk factors that may contribute to unintended weight loss, undernutrition, dehydration, poor food/fluid intake, and inability to eat independently. It is important to use a validated nutrition screening tool and to rescreen individuals after any significant change in condition. (Refer to the next page for a list of Validated Nutrition Screening Tools).

In outpatient settings, The Self MNA® Mini Nutritional Assessment may be useful (found at http://www.mna-elderly.com/forms/mini/mna_mini_english.pdf. The DETERMINE Your Health Checklist may also be used in outpatient or home and community based settings, and it can be found at http://nutritionandaging.fiu.edu/downloads/NSI_checklist.pdf.

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