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# Celiac Disease

## CD: Introduction (2009)

Guideline Title

Celiac Disease (2009) Evidence-Based Nutrition Practice Guideline

Guideline Narrative Overview

The focus of this guideline is on medical nutrition therapy (MNT) for people with celiac disease. The primary goals of MNT for people with celiac disease are to promote optimal health, to prevent and treat malabsorption/malnutrition and other comorbidities, and improve quality of life.

### Guideline Development

This guideline is intended for use by Registered Dietitians (RDs) involved in providing MNT to people with celiac disease. The guideline must be individualized, but it will assist the Registered Dietitian in successfully integrating MNT into the overall medical management of people with celiac disease. The recommendations in the guideline were based on a systematic review of the literature. Topics include:

- Long-term effectiveness of a gluten-free dietary pattern on bone density, hematological variables, villous atrophy, pregnancy outcomes, neurological symptoms and gastrointestinal symptoms
- Inclusion of oats in the dietary pattern
- Quality of life

The recommendations are based on the work performed by the American Dietetic Association Celiac Disease expert work group. The number of supporting documents for these topics is below:

- *Recommendations:* Seventeen (17)
- *Conclusion Statements:* Ten (10)
- *Evidence Summaries:* Ten (10)
- *Article Worksheets:* One hundred and fifty-six (156)

### Application of the Guideline

This guideline will be accompanied by a set of companion documents (i.e., a toolkit) to assist the practitioner in applying the guideline. The toolkit will contain materials such as the Medical Nutrition Therapy protocol, documentation forms, outcomes management tools, client education resources and case studies. The toolkit is currently under development and will undergo pilot-testing through the ADA's Dietetic Practice-Based Research Network prior to publication.

### Revision

The literature search will be repeated for each guideline topic on an annual basis to identify new research that has been published since the previous search was completed. Based on the quantity and quality of new research, a determination will be made about whether the new information could change the published recommendation or rating.

If a revision is unwarranted, then the search is recorded, dated and saved until the next review and no further action is taken. If the determination is that there could be a change in the recommendation or rating, then the supporting evidence analysis question(s) will be re-analyzed following the standard ADA Evidence Analysis Process (see ADA *Evidence Analysis Manual*).

When the analysis is completed, the expert workgroup will approve and re-grade the conclusion statements and recommendations. The guideline will undergo a complete revision every three to five years.

### Medical Nutrition Therapy and Celiac Disease

Scientific evidence supports the effectiveness of medical nutrition therapy to increase effectiveness of therapy for celiac disease. Topics included in this guideline are:

- Medical nutrition therapy and dietitian intervention
- Gluten-free dietary pattern
- Inclusion of oats in the dietary pattern
- Quality of life
- Education

The Registered Dietitian plays an integral role on the interdisciplinary care team by determining the optimal nutrition prescription and developing the nutrition care plan for patients undergoing therapy for celiac disease. Based on the patient's treatment plan and comorbid conditions, other nutrition practice guidelines, such as weight management and diabetes care guidelines, may be needed in order to provide optimal treatment.

### Populations to Whom This Guideline May Apply

This guideline applies to people with celiac disease.

### Other Guideline Overview Material

For more details on the guideline components, use the links on the left to access:

- [Scope of Guideline](#)
- [Statement of Intent](#)
- [Guideline Methods](#)
- [Implementation of the Guideline](#)

- Benefits and Harms of Implementating the Recommendations.

### **Contraindications**

Clinical judgment is crucial in the application of these guidelines. Careful consideration should be given to the application of these guidelines for patients with significant medical co-morbidities.

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# **Celiac Disease**

## **CD: Scope of Guideline (2009)**

Below, you will find a list of characteristics that describe the Scope of this Guideline.

Guideline Category

Assessment of Therapeutic Effectiveness, Counseling, Evaluation, Management, Treatment

Clinical Specialty

Allergy and Immunology, Critical Care, Endocrinology, Family Practice, Gastroenterology, Hematology, Neurology, Nutrition, Obstetrics and Gynecology, Pediatrics, Rheumatology

Intended Users

Registered Dietitians, Advanced Practice Nurses, Allied Health Personnel, Nurses, Pharmacists, Physician Assistants, Physicians, Social Workers, Students

Guideline Objective(s)

### **Overall Objective**

- To provide MNT guidelines for celiac disease to promote optimal health, prevent and treat malabsorption/malnutrition and other comorbidities, and improve quality of life.

### **Specific Objectives**

- To define evidence-based celiac disease nutrition recommendations for registered dietitians (RDs) that are carried out in collaboration with other healthcare providers
- To guide practice decisions that integrate medical, nutritional and behavioral strategies
- To achieve consistency in practice among RDs
- To provide the RD with data to make recommendations to adjust MNT or recommend other therapies to achieve desired outcomes
- To enhance the quality of life for the individual with celiac disease, utilizing customized strategies based on the individual's preferences, lifestyle and goals
- To develop guidelines for interventions that have measurable clinical outcomes
- To define the highest quality of care within cost constraints of the current healthcare environment.

Target Population

Infant (1 to 23 months), Child (6 to 12 years), Adolescent (13 to 18 years), Adult (19 to 44 years), Middle Age (45 to 64 years), Aged (65 to 79 years), Male, Female

Target Population Description

People with celiac disease.

Interventions and Practices Considered

This guideline is based on ADA's Nutrition Care Process and Model, which involves the following steps:

- Nutrition Assessment
- Nutrition Diagnosis
- Nutrition Intervention
- Nutrition Monitoring and Evaluation.

This guideline addresses topics that correspond to the following areas of the Nutrition Care Process. Please refer to the Algorithms in this guideline for a more detailed view of the recommendations and their application within the Nutrition Care Process.

- I. Referral to a Registered Dietitian
- II. Medical Nutrition Therapy

### **A. Nutrition Assessment**

Below you will find the nutrition assessment terms related to celiac disease care from *International Dietetics & Nutrition Terminology Reference Manual. Standardized Language for the Nutrition Care Process*. Third Edition.

1. Client history
  - Medical/health history
  - Medication and supplement history
  - Social history

- Personal history
- 2. Biochemical data—relevant laboratory values
- 3. Anthropometric measurements
  - Height, weight and BMI
  - Weight change rate
- 4. Food/nutrition history
  - Food intake
  - Nutrition and health awareness
  - Physical activity and exercise
  - Food availability
  - Psychosocial and economic issues impacting nutrition therapy
  - Consideration of co-morbid conditions and need for additional modifications in nutrition care plan
- 5. Physical examination findings

## **B. Nutrition Diagnosis**

Below you will find the nutrition diagnoses related to celiac disease care from *International Dietetics & Nutrition Terminology Reference Manual. Standardized Language for the Nutrition Care Process*. Third Edition.

- Inadequate energy intake
- Excessive energy intake
- Inadequate oral food/beverage intake
- Excessive oral food/beverage intake
- Inadequate intake from enteral/Parenteral nutrition
- Excessive intake from enteral/Parenteral nutrition
- Inappropriate infusion of enteral/Parenteral nutrition
- Inadequate fluid intake
- Excessive fluid intake
- Excessive alcohol intake
- Evident protein-energy malnutrition
- Inadequate fiber intake
- Excessive fiber intake
- Altered GI function
- Altered nutrition-related laboratory values
- Underweight
- Involuntary weight loss
- Overweight/obesity
- Involuntary weight gain
- Food and nutrition-related knowledge deficit
- Swallowing difficulty
- Biting/Chewing (Masticatory) difficulty
- Physical inactivity
- Inability or lack of desire to manage self-care
- Impaired ability to prepare foods/meals
- Self-feeding difficulty
- Limited access to food

## **C. Nutrition Intervention (Planning and Implementation)**

Individualized prescription based on:

1. Food/Nutrition Intervention
2. Physical activity Interventions
3. Behavioral Interventions
4. Pharmacotherapy, when indicated

Below you will find the nutrition interventions related to celiac disease care from *International Dietetics & Nutrition Terminology Reference Manual. Standardized Language for the Nutrition Care Process*. Third Edition.

### Meals and snacks

- Enteral or Parenteral nutrition
- Medical Food Supplements
- Bioactive Substance Supplements
- Feeding Assistance
- Feeding Environment
- Comprehensive nutrition education
- Nutrition counseling
- Strategies
- Coordination of nutrition care
- Discharge planning and transfer of nutrition care to new setting or provider

## **D. Monitoring and Evaluation**

The monitoring or progress, measuring of outcomes, and evaluating of outcomes against criteria to determine changes in specific indicators of MNT outcomes.

Below you will find the nutrition monitoring and evaluation terms related to celiac disease care from *International Dietetics & Nutrition Terminology Reference Manual. Standardized Language for the Nutrition Care Process*. Third Edition.

- Nutrition-related ADLs and IADLs
- Physical activity

- Food and nutrient intake outcomes
  - Nutrition-related physical sign/symptoms outcomes
  - Nutrition-related patient/client centered outcomes
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For more information on the guideline components, use the links on the left to access:

- *Scope of Guideline*
- *Statement of Intent*
- *Guideline Methods*
- *Implementation of the Guideline*
- *Benefits and Harms of Implementing the Recommendations.*

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## Celiac Disease

### CD: Statement of Intent (2009)

#### Statement of Intent

Evidence-based nutrition practice guidelines are developed to help dietetic practitioners, patients and consumers make shared decisions about health care choices in specific clinical circumstances. If properly developed, communicated and implemented, guidelines can improve care.

While they represent a statement of best practice based on the latest available evidence at the time of publishing, they are not intended to overrule professional judgment. Rather, they may be viewed as a relative constraint on individual clinician discretion in a particular clinical circumstance. The independent skill and judgment of the health care provider must always dictate treatment decisions. These nutrition practice guidelines are provided with the express understanding that they do not establish or specify particular standards of care, whether legal, medical or other.

#### The Role of Patient Preference

This guideline recognizes the role of patient preferences for possible outcomes of care, when the appropriateness of a clinical intervention involves a substantial element of personal choice or values. With regard to types of evidence that are associated with particular outcomes, Shaughnessy and Slawson (1-3) describe two major classes. Patient-oriented evidence that matters (POEM) deals with outcomes of importance to patients, such as changes in morbidity, mortality or quality of life. Disease-oriented evidence (DOE) deals with surrogate end-points, such as changes in laboratory values or other measures of response. Although the results of DOE sometimes parallel the results of POEM, they do not always correspond.

When possible, ADA recommends using POEM-type evidence rather than DOE. When DOE is the only guidance available, the guideline indicates that key clinical recommendations lack the support of outcomes evidence.

#### References

1. Slawson DC, Shaughnessy AF. Becoming an information master: using POEMs to change practice with confidence. *Patient-Oriented Evidence that Matters. J Fam Pract.* 2000 Jan; 49 (1): 63-67. Erratum in: *J Fam Pract.* 2000 Mar; 49 (3): 276.
  2. Slawson DC, Shaughnessy AF, Ebell MH, Barry HC. Mastering medical information and the role of POEMs--Patient-Oriented Evidence that Matters. *J Fam Pract.* 1997 Sep; 45 (3): 195-196.
  3. Shaughnessy AF, Slawson DC. POEMs: patient-oriented evidence that matters. *Ann Intern Med.* 1997 Apr 15; 126 (8): 667.
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## Celiac Disease

### CD: Guideline Methods (2009)

General and Specific Methods for Celiac Disease Evidence Based Nutrition Practice Guideline

Below are links to both the general methods that ADA has put in place for evidence analysis and creating the guidelines, as well as the specific search methods and criteria for each question.

#### General Methods

[Click here](#) to view a description of the ADA's process of evidence analysis and guideline creation.

#### Methods for Specific Topics

Click Specific Topics Searched to view descriptions of search criteria and findings for each topic covered in this guideline.

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## CD: Specific Topics Searched (2009)

Each evidence analysis topic has a link to supporting evidence, where the Search Plan and Results can be found. Here, you can view when the search plan was performed, inclusion and exclusion criteria, search terms, databases that were searched and the excluded articles.

Below are a list of the recommendations with links to the relevant search plans. Some recommendations are supported by multiple conclusion statements and therefore have multiple search plans listed.

*Consensus*-rated recommendations were not developed using ADA's evidence analysis process, but based on consensus documents. Therefore, these recommendations do not have links to *Search Plans*.

To see the recommendations, click on Major Recommendations.

### Celiac Disease (CD) Major Recommendations

#### *Nutrition Assessment*

CD: Assessment of Food/Nutrition-Related History

[Search Plan and Results](#)  
[Search Plan and Results](#)

CD: Assess Factors Affecting Quality of Life

[Search Plan and Results](#)

CD: Bone Density Screening

[Search Plan and Results](#)

CD: Assess Biochemical Data and Results of Medical Procedures

[Search Plan and Results](#)  
[Search Plan and Results](#)

CD: Assess Gastrointestinal Symptoms

[Search Plan and Results](#)

#### *Nutrition Intervention*

CD: Inclusion of Gluten-Free Oats

[Search Plan and Results](#)

CD: Meeting Nutritional Needs

[Search Plan and Results](#)

CD: Calcium/Vitamin D for Reduced Bone Density

[Search Plan and Results](#)

CD: Iron Supplementation for Iron Deficiency Anemia

[Search Plan and Results](#)

CD: Gluten-Free Dietary Pattern

[Search Plan and Results](#)  
[Search Plan and Results](#)  
[Search Plan and Results](#)  
[Search Plan and Results](#)  
[Search Plan and Results](#)  
[Search Plan and Results](#)  
[Search Plan and Results](#)

#### *Nutrition Monitoring and Evaluation*

CD: Monitor and Evaluate Dietary Compliance

[Search Plan and Results](#)  
[Search Plan and Results](#)

CD: Monitor and Evaluate Factors Affecting Quality of Life

[Search Plan and Results](#)  
[Search Plan and Results](#)  
[Search Plan and Results](#)

CD: Monitor and Evaluate Gastrointestinal Symptoms

[Search Plan and Results](#)

The following recommendations were not analyzed through ADA's evidence analysis, but developed based on available consensus documents. See these specific recommendations and references under [Major Recommendations](#).

- CD: Celiac Disease and Medical Nutrition Therapy

- CD: Provide Resources and Education on Label Reading
- CD: Education on Food Cross-Contamination
- CD: Coordination of Care.

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## Celiac Disease

### CD: Implementation of the Guideline (2009)

#### Implementation of the Guideline

This publication of the Celiac Disease guideline is an integral part of plans for disseminating the ADA MNT evidence-based recommendations to all dietetics practitioners. National implementation workshops at various sites around the country and during the ADA Food Nutrition Conference Expo (FNCE) are planned. Additionally, there are recommended dissemination and adoption strategies for local use of the *ADA Celiac Disease Evidence-Based Nutrition Practice Guideline*.

The guideline development team recommended multi-faceted strategies to disseminate the guideline and encourage its implementation. Management support and learning through social influence are likely to be effective in implementing guidelines in dietetic practice. However, additional interventions may be needed to achieve real change in practice routines.

Implementation of the *Celiac Disease Evidence-Based Nutrition Practice Guideline* will be achieved by announcement at professional events, presentations and training. Some strategies include:

- **National and Local Events** – State dietetic association meetings and media coverage will help launch the guideline
- **Local Feedback Adaptation** – Presentation by members of the work group at peer review meetings and opportunities for CEUs for courses completed
- **Education Initiatives** – The guideline and supplementary resources will be freely available for use in the education and training of dietetic interns and students in approved Commission on Accreditation of Dietetics Education (CADE) programs
- **Resources** – Expert members of the guideline team will prepare articles for publications. Materials will be provided that include PowerPoint presentations, full guidelines and pre-prepared case studies. Establishment of a Peer Network is also planned.
- **Practical Tools** – Some of the tools that will be developed to help implement the guideline include specially designed resources, such as clinical algorithms, slide presentations, training and toolkits.

Specific distribution strategies include:

*Publication in full:* The guideline is available electronically at the ADA Evidence Analysis Library website ([www.adaevidencelibrary.com](http://www.adaevidencelibrary.com)) and announced to all ADA Dietetic Practice Groups. The ADA Evidence Analysis Library will also provide downloadable supporting information and links to relevant position papers.

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## Celiac Disease

### CD: Benefits and Risks/Harms of Implementation (2009)

#### Benefits and Risks/Harms of Implementing the Recommendations

Safety issues must be reviewed carefully for each individual. General benefits and risks associated with implementation of the guideline are addressed for each recommendation.

#### Potential Benefits

A primary goal of implementing these recommendations is to provide MNT guidelines for Celiac Disease to promote optimal health, prevent and treat malabsorption/malnutrition and other comorbidities and improve quality of life. Potential benefits include a person's ability to achieve optimal nutrition.

Although costs of medical nutrition therapy (MNT) sessions and reimbursement vary, MNT is essential for improved outcomes. MNT education can be considered cost effective when considering the benefits of nutrition interventions on the onset and progression of comorbidities versus the cost of the intervention.

#### Risk and Harm Considerations

When using these recommendations:

- Review the patient's age, socioeconomic status, cultural issues, health history, and other health conditions.
- Consider referral to other specialties: Allergy and Immunology, Endocrinology, Gastroenterology, Hematology,

Neurology, Obstetrics and Gynecology, Pediatrics, Family Practice, Rheumatology

- Consider referral to a behavioral specialist if psychosocial issues are a concern.
- Consider a referral to social services to assist patients with financial arrangements if economic issues are a concern.
- Use clinical judgment in applying the guidelines when evaluating patients with celiac disease.

In addition to the above, a variety of barriers may hinder the application of these recommendations.

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