

1 — PHYSICIAN VISIT AT TIME OF DIAGNOSIS

Children and adolescents with celiac disease may be at risk for nutritional deficiencies, poor growth, bone health concerns, anemia, other autoimmune diseases, and more. **At diagnosis, a pediatrician or pediatric gastroenterologist should assess for the following:**

- Assess growth patterns as appropriate for the child's age to monitor overall health and development.
- Order celiac serology (e.g. anti-DGP IgA and anti-tTg IgA) if not previously obtained. DQ2/DQ8 genetic testing may be indicated based on clinical presentation.
- Recommend family screening (DQ2/DQ8 genetic testing and celiac serology to include anti-tTg IgA and total IgA to exclude IgA deficiency).
- Recommend a dietitian expert in celiac disease and the gluten-free diet to provide education and counseling.
- Assess hepatitis B, flu, and pneumococcal vaccination status.
- Order a bone density scan if clinically indicated.
- Order routine tests (complete blood cell count, iron studies, vitamin B studies, thyroid function tests with thyrotropin, liver enzymes, calcium, phosphate, 25-hydroxy vitamin D, copper, and zinc levels).
- Recommend a mental health professional, as needed, to support coping with a chronic disease, navigating the psychosocial challenges of a gluten-free diet, and managing barriers such as food access or insecurity.
- Recommend a gluten-free multivitamin and additional supplementation as needed.
- Provide a diagnosis letter for school (e.g. K-12 and post secondary education) and other federally funded activities.

Celiac disease can affect growth due to intestinal damage caused by long-term gluten consumption, which prevents the body from properly absorbing nutrients.

tTg-IgA antibodies tend to decrease after 6-12 months on a strict, gluten-free diet, but may take longer in some patients. A baseline measure is needed to track this. However, there is not enough evidence to show that this is a useful measure of dietary compliance.

First degree family members (parents, siblings, children) have a 1 in 10 risk of developing celiac disease compared to the 1 in 100 risk in the general population.

The only treatment for celiac disease is a strict, gluten-free diet. Referral to a dietitian expert in celiac disease is the best way to provide thorough nutritional assessment and education.

An annual flu shot and pneumococcal vaccine is recommended. Most children already receive the pneumococcal vaccine as part of routine childhood immunizations, and additional doses are usually not needed unless there are certain medical conditions (e.g. IBD).

Loss of bone mass due to malnutrition is common in celiac disease. Long-term adherence to the gluten-free diet leads to significant improvement in bone density.

Celiac disease patients are at risk for anemia, autoimmune thyroid disease, liver disease, and mineral deficiencies. Generally, these issues are resolved after 2 years on a strict, gluten-free diet. It is critical that your physician checks for small intestine normalization to prevent further complications.

Individuals with celiac disease may experience mental health concerns, including symptoms of depression or anxiety. Incorporating mental health screening and access to appropriate support can be an important component of comprehensive care.

Commonly, people with celiac disease are deficient in fiber, iron, calcium, magnesium, zinc, folate, niacin, riboflavin, vitamin B12, and vitamin D, as well as in calories and protein. After treatment with the gluten-free diet, most patients' small intestines recover and are able to properly absorb nutrients again.

A diagnosis letter is needed to establish a 504 Plan or other accommodations plan (e.g. college) so the patient can safely access gluten-free food. Celiac disease is considered a disability under the Americans With Disabilities Act.

2

FOLLOW-UP VISIT WITH PHYSICIAN

Follow-up visits should occur at 3-6 months and 12 months after initial diagnosis, and then annually thereafter. **At these visits, your pediatrician or pediatric gastroenterologist should check for the following:**

- Re-assess clinically relevant data, such as growth, symptoms, bloodwork (e.g. iron studies, B-vitamins, thyroid function tests, and zinc), and overall health.
- Re-order celiac serology (anti-DGP IgA and anti-tTg IgA).
- Re-assess hepatitis B immunization status if previously abnormal, at 12 month visit.
- Recommend a flu shot annually.
- Recommend a mental health professional, as needed, to support coping with a chronic disease, navigating the psychosocial challenges of a gluten-free diet, and managing barriers such as food access or insecurity.
- Consider repeat small intestinal biopsy at 3-5 years to assess dietary compliance and rule out non-responsive celiac disease.
- Perform a complete physical exam upon indication at the 3-6 month visit, and annually.
- Recommend a dietitian to provide education and counseling to support individual nutrition needs.
- Repeat bone density scan if clinically indicated.
- Ensure the patient is getting the necessary accommodations needed to support their gluten-free diet in school and other federally funded activities.

Most lab values typically start to normalize once a child starts a gluten-free diet. Symptoms may take time to improve and do not necessarily indicate that a child is being exposed to gluten.

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Up to 70% of celiac disease patients are non responsive to hepatitis B vaccine before starting a strict, gluten-free diet.

Individuals with celiac disease may be at higher risk for hospitalization from the flu.

Children with celiac disease may experience mental health concerns, including anxiety, depression, or disordered eating. Incorporating mental health screening and, when indicated, referral to appropriate support can help families cope with the psychosocial challenges of a gluten-free diet, chronic disease management, and barriers such as food access or insecurity.

A duodenal biopsy is suggested to be the only tool that can identify persistent villous atrophy (small intestine damage).

Follow up appointments are important. Your doctor may perform routine tests and screen you for other conditions if indicated.

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3

INITIAL DIETITIAN VISIT

The only treatment for celiac disease is a strict, gluten-free diet. Working with a dietitian on age-appropriate nutrition recommendations is critical. **At your initial visit, your dietitian should:**

Evaluate clinical status, symptom course, and relevant biochemical markers to assess nutritional status, disease control, and potential complications.

Celiac disease impacts your child's ability to absorb nutrients from food, which can lead to malnutrition, nutrient deficiencies, and symptoms in any part of the body.

Document food and nutrition intake by obtaining a comprehensive diet history.

History should include current dietary intake, food intolerances (e.g., lactose), physical activity pattern, family situation, dining in / out practices, ability to prepare or obtain gluten-free meals, food availability, and psychosocial or economic issues impacting nutrition therapy.

Assess prescribed and over-the-counter medications and supplements for their potential gluten content and potential for food or drug interaction.

Though uncommon, gluten-containing ingredients may be present in medications. Supplements are poorly regulated, and therefore only products with a gluten-free label should be purchased. Always inform your dietitian about supplements your child is taking.

Provide clear age-appropriate education on the gluten-free diet.

Your dietitian should provide education on: (1) reading food and supplement labels, (2) identifying foods and ingredients that are appropriate to include or avoid, (3) strategies to reduce the risk of gluten cross contact during food storage and preparation, and (4) how the gluten-free diet may affect the dietary treatment of other conditions.

Assess understanding of the gluten-free diet, application of dietary recommendations, relationship with food, and coping with dietary demands.

Your dietitian will assist in setting age-appropriate behavioral goals that are focused on maintaining a gluten-free diet.

Collaborate with physicians and mental health professionals as indicated.

Provide recommendations to other healthcare providers as indicated, including follow-up lab testing and evaluation of mental health as appropriate.

Assess gastrointestinal and extra-intestinal symptoms of celiac disease.

Your dietitian can provide support for management of any symptoms that may be present and have an indication for dietary intervention.

Assess factors that could affect quality of life, such as how the gluten-free diet will affect school, religious and social activities, and the family's economic status.

Provide resources (e.g. printed materials, websites, locally available foods, restaurants, and social support) as needed. Support the family in getting necessary accommodations at school as needed.

4

FOLLOW-UP VISIT WITH DIETITIAN

Follow-up visits should occur at a timeframe mutually agreed upon between you and your dietitian. Most people will have multiple follow up visits. **At these visits, your dietitian should:**

Re-evaluate clinical status, symptom course, and relevant biochemical markers to assess nutritional status, disease control, and potential complications.

Celiac disease impacts your ability to absorb nutrients from food, which can lead to malnutrition, nutrient deficiencies, and symptoms in any part of the body.

Document food and nutrition intake by obtaining a comprehensive diet history.

History should include current dietary intake, food intolerances (e.g., lactose), physical activity pattern, family situation, dining in / out practices, ability to prepare or obtain gluten-free meals, food availability, and psychosocial or economic issues impacting nutrition therapy.

Re-assess prescribed and over-the-counter medications and supplements for their potential gluten content and potential for food or drug interaction.

Though uncommon, gluten-containing ingredients may be present in medications. Supplements are poorly regulated, and therefore only products with a gluten-free label should be purchased. Always inform your dietitian about supplements your child is taking.

Make adjustments to the gluten-free diet plan as indicated.

Your dietitian may make adjustments to your child's plan based on intake of key nutrients such as calcium, vitamin D, iron, B vitamins, and fiber, changes in health status, new diagnoses, cooking skills, availability of gluten-free food, and / or barriers to learning.

Re-assess understanding of the gluten-free diet, application of dietary recommendations, relationship with food, and coping with dietary demands.

Your dietitian will assist in setting age-appropriate behavioral goals that are focused on maintaining a gluten-free diet.

Collaborate with physicians and mental health professionals as indicated.

Provide recommendations to other healthcare providers as indicated, including follow-up lab testing and evaluation of mental health as appropriate.

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Provide resources (e.g. printed materials, websites, locally available foods, restaurants, and social support) as needed. Support the family in getting necessary accommodations at school as needed.