

1 — PHYSICIAN VISIT AT TIME OF DIAGNOSIS

Celiac disease is a serious medical condition that requires long-term follow-up to maintain health and prevent future complications. **At time of diagnosis, your physician should:**

- Perform a complete physical exam, including an assessment of growth or weight trends over time and signs of nutrient deficiencies.**
- Order celiac serology (e.g. anti-DGP IgA and anti-tTg IgA), if not previously obtained.**
- Recommend family screening (DQ2/DQ8 genetic testing and celiac serology to include anti-tTg IgA, anti-DGP IgG, and total IgA to exclude IgA deficiency).**
- 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.**
- Assess hepatitis B, flu, and pneumococcal vaccination status.**
- Order a bone density scan (optional).**
- Order routine tests (complete blood cell count, iron studies, vitamin B studies, thyroid function tests with TSH, liver enzymes, calcium, phosphate, 25-hydroxy vitamin D, and zinc levels).**
- Recommend a dietitian expert in celiac disease and the gluten-free diet to provide education and counseling.**
- Recommend a gluten-free multivitamin and additional supplementation as needed.**

Changes in weight may occur after initiation of a gluten-free diet and can vary between individuals. These changes may reflect improvements in intestinal healing and nutrient absorption. A general physical exam may also reveal signs of vitamin and mineral deficiencies, such as changes in the nails, lips, tongue, skin (e.g., rashes), abdominal findings, or the presence of a goiter.

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.

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.

Up to 70% of celiac disease patients are non responsive to hepatitis B vaccine before starting a gluten-free diet; therefore, vaccination may be more effective after a few months on a gluten-free diet. An annual flu shot, and the pneumococcal vaccine are strongly recommended.

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. Your medical team will determine if this is appropriate for you.

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.

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.

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.

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FOLLOW-UP VISIT WITH PHYSICIAN

Follow-up visits typically occur at 3-6 months and 12 months after initial diagnosis, and then annually thereafter.

At these visits, your physician should:

<input type="checkbox"/> Assess symptoms at each visit.	<p>Symptoms may take time to improve and do not necessarily indicate that a person is being exposed to gluten.</p>
<input type="checkbox"/> 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.	<p>tTg-IgA antibodies tend to decrease or completely return within normal limits after 6-12 months on a strict, gluten-free diet. However, there is not enough evidence to show that this is a useful measure of dietary compliance.</p>
<input type="checkbox"/> Assess hepatitis B immunization status if previously abnormal, at 12 month visit.	<p>Up to 70% of celiac disease patients are non responsive to hepatitis B vaccine before starting a strict, gluten-free diet.</p>
<input type="checkbox"/> Recommend a flu shot annually.	<p>Individuals with celiac disease may be at higher risk for hospitalization from the flu.</p>
<input type="checkbox"/> 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.	<p>Individuals 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 patients cope with the psychosocial challenges of a gluten-free diet, chronic disease management, and barriers such as food access or insecurity.</p>
<input type="checkbox"/> Consider repeat small intestinal biopsy at 1-3 years to assess intestinal healing and rule out refractory celiac disease.	<p>A duodenal biopsy is suggested to be the only tool that can identify persistent villous atrophy (small intestine damage).</p>
<input type="checkbox"/> Perform a complete physical exam upon indication at the 3-6 month visit, and annually.	<p>Follow up appointments are important. Your doctor may perform routine tests and screen you for other conditions if indicated.</p>
<input type="checkbox"/> Recommend a dietitian to provide education and counseling as clinically indicated.	<p>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.</p>
<input type="checkbox"/> Repeat bone density scan at 2-3 years, if previously abnormal.	<p>Loss of bone mass due to malnutrition is common in celiac disease. Long-term adherence to a gluten-free diet leads to significant improvement in bone density. People over 50 with celiac disease are at higher risk for bone fractures.</p>

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INITIAL DIETITIAN VISIT

The only treatment for celiac disease is a strict, gluten-free diet. **At time of diagnosis, 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 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, 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 you are taking.

Provide clear 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 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 religious and social activities and economic status.

Provide resources (e.g. printed materials, websites, locally available foods, restaurants, and social support) as needed.

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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:**

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| <input type="checkbox"/> Re-evaluate clinical status, symptom course, and relevant biochemical markers to assess nutritional status, disease control, and potential complications. | <p>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.</p> |
| <input type="checkbox"/> Document food and nutrition intake by obtaining a comprehensive diet history. | <p>History should include current dietary intake, food intolerances (e.g., lactose), physical activity pattern, dining in / out practices, ability to prepare or obtain gluten-free meals, food availability, and psychosocial or economic issues impacting nutrition therapy.</p> |
| <input type="checkbox"/> Re-assess prescribed and over-the-counter medications and supplements for their potential gluten content and potential for food or drug interaction. | <p>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 you are taking.</p> |
| <input type="checkbox"/> Make adjustments to the gluten-free diet plan as indicated. | <p>Your dietitian may make adjustments to your 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.</p> |
| <input type="checkbox"/> Re-assess understanding of the gluten-free diet, application of dietary recommendations, relationship with food, and coping with dietary demands. | <p>Your dietitian will assist in setting behavioral goals that are focused on maintaining a gluten-free diet.</p> |
| <input type="checkbox"/> Collaborate with physicians and mental health professionals as indicated. | <p>Provide recommendations to other healthcare providers as indicated, including follow-up lab testing and evaluation of mental health as appropriate.</p> |
| <input type="checkbox"/> Re-assess gastrointestinal and extra-intestinal symptoms of celiac disease. | <p>Your dietitian can provide support for management of any symptoms that may be present and have an indication for dietary intervention.</p> |
| <input type="checkbox"/> Re-assess factors that could affect quality of life, such as how the gluten-free diet will affect religious and social activities and economic status. | <p>Provide resources (e.g. printed materials, websites, locally available foods, restaurants, and social support) as needed.</p> |