ADULT CELIAC DISEASE **FOLLOW-UP CHECKLIST**

Celiac Disease FOUNDATION®

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:**

HELPFUL TIPS

- ☐ Perform a complete physical exam including determination of BMI and examinations for enlarged lymph nodes and occult blood in the stool
  - Normally, BMI increases on a gluten-free diet. However, for the approximately 40% of newly diagnosed patients who are overweight, BMI may decrease due to a lessening in feeling hungry. Enlarged lymph nodes and blood in the stool might be a sign of other complications.
- ☐ Order celiac serology (anti-DGP IgA and anti-tTg IgA) and DQ2/DQ8 genetic testing, if not previously obtained
  - tTg-IgA antibodies tend to decrease or completely return within normal limits after 6-12 months on a strict, gluten-free diet. 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.
- ☐ 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)
  - 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.
- ☐ Recommend a mental health professional to address the psychosocial aspects of going gluten-free and coping with a chronic disease, as needed
  - Depression and anxiety are common conditions in celiac disease patients. Many patients benefit from mental health evaluation and treatment.
- ☐ Assess hepatitis B, flu, and pneumococcal vaccination status
  - Up to 70% of celiac disease patients are nonresponsive to hepatitis B vaccine before starting a strict, gluten-free diet. An annual flu shot, and the pneumococcal vaccine are strongly recommended.
- ☐ Order bone densitometry
  - 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 physician will need a baseline measurement in order to confirm an increase in bone mass at time of follow-up.
- ☐ 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)
  - 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.
- ☐ Recommend a dietitian expert in celiac disease and the gluten-free diet to provide education and counseling
  - 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.
- ☐ Recommend a gluten-free multivitamin and additional supplementation as needed
  - 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. Deficiencies in copper and vitamin B6 are also possible, but less common. After treatment with the gluten-free diet, most patients' small intestines recover and are able to properly absorb nutrients again. However, patients may continue to be vitamin B deficient as the gluten-free diet may not provide sufficient supplementation.

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 physician should:**

HELPFUL TIPS

- ☐ Assess symptoms at each visit
- ☐ Order celiac serology (anti-DGP IgA and anti-tTg IgA)
  - 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.
- ☐ Assess hepatitis B immunization status if previously abnormal, at 12 month visit
  - Up to 70% of celiac disease patients are nonresponsive to hepatitis B vaccine before starting a strict, gluten-free diet.
- ☐ Recommend a flu shot annually
- ☐ Recommend a mental health professional to address the psychosocial aspects of going gluten-free and coping with a chronic disease, as needed
  - Depression and anxiety are common conditions in celiac disease patients. Many patients benefit from mental health evaluation and treatment.
- ☐ Consider repeat small intestinal biopsy at 3-5 years to assess dietary compliance and rule out refractory celiac disease
  - A duodenal biopsy is suggested to be the only tool that can identify persistent villous atrophy (small intestine damage.)
- ☐ Perform a complete physical exam upon indication at the 3-6 month visit, and annually
- ☐ Repeat routine tests if previously abnormal at 3-6 month visit, and annually
- ☐ Order other tests as clinically indicated annually
- ☐ Recommend a dietitian to provide education and counseling as clinically indicated, annually
  - 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.
- ☐ Repeat bone densitometry at 2-3 years, if previously abnormal
  - 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.

3 INITIAL DIETITIAN VISIT

The only treatment for celiac disease is a strict, gluten-free diet. **At time of diagnosis, your dietitian should:**

- ☐ Evaluate height, weight, weight history, growth history, relationship to family stature, BMI, biochemical data
- ☐ Document food and nutrition history by obtaining a comprehensive diet history
- ☐ Assess prescribed and over-the-counter medications and supplements for their potential gluten content and potential for food or drug interaction
- ☐ Assess knowledge base, motivation level, and readiness to change to the gluten-free diet
- ☐ Provide clear instruction in the gluten-free diet
- ☐ Educate on how the gluten-free diet might affect dietary treatment of other illnesses
- ☐ Collaborate with physicians and mental health professionals as indicated
- ☐ Review personal and family medical history, including other autoimmune diseases
- ☐ Document food experience including any previously prescribed or self-imposed food restrictions
- ☐ Assess gastrointestinal symptoms such as type, frequency, and volume of bowel function, abdominal pain, bloating, nausea, and vomiting
- ☐ Assess factors that could affect quality of life, such as how the gluten-free diet will affect religious and social activities and economic status
- ☐ Assist in setting behavioral goals that are focused on maintaining a gluten-free diet
- ☐ Provide resources (printed materials, websites, locally available foods, restaurants, and social support)

HELPFUL TIPS

History should include (1) current dietary intake (grain intake, sources of B vitamins, fiber, calcium iron, and vitamin D), (2) food intolerances (e.g., lactose), (3) physical activity pattern, (4) dining in/out practices, (5) food availability, (6) psychosocial or economic issues impacting nutrition therapy.

Your dietitian should explain: (1) reading of food and supplement nutrition labels, (2) foods and ingredients allowed and to avoid, (3) prevention of cross-contact with gluten-containing foods in food preparation, (4) evaluation of gluten content of medications, (5) introduction of gluten-free oats into the diet.

Your dietitian should provide recommendations to other healthcare providers, such as rechecking celiac disease antibodies and other lab data, and the need for evaluation of bone density and mental health status.

Celiac disease is genetic, with first degree (parent, sibling, child) relatives having a 1 in 10 risk of developing celiac disease. People with celiac disease are also at increased risk of developing multiple autoimmune disorders.

4 FOLLOW-UP VISIT WITH DIETITIAN

Follow-up visits should occur at 2-4 weeks and 6-12 months after initial diagnosis. Additional visits may be recommended by your physician due to non-compliance with a strict, gluten-free diet.
At these visits, your dietitian should:

HELPFUL TIPS

- ☐ Re-evaluate weight, BMI, changes in growth pattern, celiac disease antibodies, and other biochemical data
- ☐ Document food and nutrition history by obtaining a comprehensive diet history
  - History should include (1) current dietary intake (grain intake, sources of B vitamins, fiber, calcium, iron, and vitamin D), (2) food intolerances (e.g., lactose), (3) physical activity pattern, (4) dining in/out practices, (5) food availability, (6) psychosocial or economic issues impacting nutrition therapy.
- ☐ Reassess gastrointestinal symptoms such as type, frequency, and volume of bowel function, abdominal pain, bloating, nausea, and vomiting
- ☐ Reassess factors that could affect quality of life, such as how the gluten-free dietary pattern is affecting religious and social activities and economic status
- ☐ Make adjustments to the gluten-free diet plan as indicated
  - Your dietitian should adjust for (1) calorie intake, calcium, and vitamin D intake, iron supplementation, B vitamin, and fiber intake, (2) changes in medical status, (3) consumption of whole/enriched gluten-free grains, (4) addition of a gluten-free, age, and gender appropriate multivitamin and mineral supplement.
- ☐ Collaborate with physicians and mental health professionals as indicated
  - Your dietitian should provide recommendations to other healthcare providers, such as rechecking celiac disease antibodies and other lab data, and the need for evaluation of bone density and mental health status.
- ☐ Review any new medical diagnoses and/or changes in management of other diagnoses such as insulin regimen changes in type 1 diabetes
- ☐ Reassess prescribed and over-the-counter medications and supplements for their potential gluten content and potential for food or drug interaction
- ☐ Reassess client's knowledge base, motivation level, and readiness to change to the gluten-free diet
- ☐ Determine adherence to the gluten-free diet and compare with expected outcomes/goals
  - Your dietitian should identify barriers to learning or ability to implement change and assist client in setting behavioral goals focused on maintaining the gluten-free diet.
- ☐ Provide resources (printed materials, websites, locally available foods, restaurants, and social support)