**PEDIATRIC** CELIAC DISEASE **FOLLOW-UP CHECKLIST**

Celiac Disease FOUNDATION®

# 1 PHYSICIAN VISIT AT TIME OF DIAGNOSIS

Children and adolescents with celiac disease often have poor nutritional status resulting in bone loss, anemia, thyroid and liver disease, and compromised hepatitis B immunization status. **At diagnosis, your pediatrician should check for the following:**

## HELPFUL TIPS

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| ☐ Height, weight, and BMI (or weight for height ratio in children younger than three years old) | Celiac disease can affect growth due to intestinal damage caused by long-term gluten consumption, which prevents the body from properly absorbing nutrients. |
| ☐ Anemia (CBC, evaluation of mean cell volume, ferritin, iron, total iron-binding capacity) | Iron deficiency anemia (IDA) occurs in up to 69% of newly diagnosed celiac disease patients. Iron studies will tell your pediatrician if supplementation is needed. |
| ☐ Liver disease (ALT and AST) | Celiac hepatitis is the most common liver disease affecting up to 60% of children at diagnosis. Liver disease is defined by an isolated elevation of ALT and AST. Liver function usually returns to normal after 6-12 months on a strict, gluten-free diet. |
| ☐ Counseling about signs and symptoms of type 1 diabetes | Celiac disease patients have a slightly increased risk of type 1 diabetes, but there is no preventative strategy to avoid developing diabetes. |
| ☐ Dietitian recommendation for dietary counseling | The only treatment for celiac disease is a strict, gluten-free diet. Referral to dietitian expert in celiac disease is the best way to provide thorough nutritional assessment and education. |
| ☐ Family screening recommendation (DQ2/DQ8 genetic testing and celiac serology to include anti-tTg IgA, anti-DGP IgG, and total IgA) | 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. |
| ☐ Zinc and other trace elements - only if severe malabsorption or prolonged delay in diagnosis | Though low in more than half of children initially diagnosed with celiac disease, zinc levels usually return to normal within four weeks of starting the gluten-free diet. |
| ☐ Vitamin D level (25-OH) | Celiac disease affects bone health due to decreased absorption of calcium and vitamin D. Screening for vitamin D deficiency will tell your pediatrician if supplementation is needed. |
| ☐ Thyroid disease (thyrotropin) | Celiac disease patients have a significant risk for developing autoimmune thyroid disease, especially Hashimoto's disease. |
| ☐ 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. |
| ☐ Counseling for multi-vitamin supplementation | People with celiac disease are often 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. |
| ☐ Mental health practitioner recommendation, as clinically indicated | Depression and anxiety are common conditions in celiac disease patients. Many patients benefit from mental health evaluation and treatment. |
| ☐ Bone health (biochemical studies and imaging) - only if severe malabsorption or prolonged delay in diagnosis | Celiac disease patients with severe malabsorption, a prolonged delay in diagnosis, or who have symptoms of bone disease including pain and rickets, as well as those who fracture easily should be screened for bone health. |

# 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 should check for the following:**

## HELPFUL TIPS

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| ☐ Height, weight, and BMI (or weight for height ratio in children younger than three years old) | Celiac disease can affect growth due to intestinal damage caused by long-term gluten consumption, which prevents the body from properly absorbing nutrients. |
| ☐ Thyroid disease (thyrotropin) | Celiac disease patients have a significant risk for developing autoimmune thyroid disease, especially Hashimoto's disease. |
| ☐ Annual flu shot | An annual flu shot is strongly recommended for celiac disease patients. |
| ☐ Vitamin D level (25-OH) - if previously abnormal | Celiac disease affects bone health due to decreased absorption of calcium and vitamin D. Screening for vitamin D deficiency will tell your pediatrician if supplementation is needed. |
| ☐ Hepatitis B virus immunization status - if previously abnormal | Up to 70% of celiac disease patients are nonresponsive to hepatitis B vaccine before starting a strict, gluten-free diet. |
| ☐ At one year, bone health (biochemical studies and imaging) - if previously abnormal | Celiac disease patients with severe malabsorption, a prolonged delay in diagnosis, or who have symptoms of bone disease including pain and rickets, as well as those who fracture easily, should be screened for bone health. |
| ☐ Mental health practitioner recommendation, as clinically indicated | Depression and anxiety are common conditions in celiac disease patients. Many patients benefit from mental health evaluation and treatment. |
| ☐ Complete blood cell count (CBC) | A complete blood cell count (CBC) is needed annually to screen for anemia. |
| ☐ Antibody testing (tTg-IgA) to monitor compliance with gluten-free diet (at least six months from start of diet) | 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. |
| ☐ Bone densitometry if patient not adhering to a gluten-free diet despite dietitian counseling | Adolescents who have poor compliance with the gluten-free diet may require a bone density scan. This should be repeated every 1-2 years until results normalize. |
| ☐ Liver disease (ALT and AST) - if previously abnormal | Celiac hepatitis is the most common liver disease affecting up to 60% of children at diagnosis. Liver disease is defined by an isolated elevation of ALT and AST. Liver function usually returns to normal after 6-12 months on a strict, gluten-free diet. |
| ☐ Zinc and other trace elements - if previously abnormal | Though low in more than half of children initially diagnosed with celiac disease, zinc levels usually return to normal within four weeks of starting a gluten-free diet. |
| ☐ Dietitian recommendation for dietary counseling, if clinically indicated | 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. |

# 3 INITIAL DIETITIAN VISIT

The only treatment for celiac disease is a strict, gluten-free diet. Age-appropriate calcium and vitamin D supplementation is recommended to combat bone loss from malnutrition. **At time of diagnosis, your dietitian should provide the following:**

## HELPFUL TIPS

- ☐ Clear understanding of the gluten-free diet for both patients and caregivers
  - Your dietitian should explain: (1) age-appropriate 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.
- ☐ Clear understanding of caloric and nutritional needs
  - Your dietitian should: (1) evaluate nutrition-related lab values, (2) provide recommendations for supplemental multi-vitamin needs, (3) provide recommendations for dietary micronutrient needs, (4) provide recommendations to treat micronutrient deficiencies if present, (5) provide recommendations for dietary fiber as appropriate.
- ☐ Evaluation of bone health studies performed (bone densitometry and blood serum markers)
  - Your dietitian should: (1) provide age-appropriate recommendations for dietary or supplemental calcium and vitamin D intake, (2) provide a clear understanding of the need for exercise to promote bone health.
- ☐ Provide resources for locally available food products, restaurants, and social support
- ☐ Creation of behavioral goals for achieving compliance with the gluten-free diet
- ☐ Evaluation of growth history in relationship to family stature with dietary interventions for catch-up growth to normal growth curve as needed
- ☐ Assess need for nutritional intervention for any co-occurring disorders (i.e. type 1 diabetes, inflammatory bowel disease, hypothyroidism, etc.)
  - Celiac disease is associated with a number of autoimmune disorders and other conditions. To learn more, visit celiac.org/relatedconditions.
- ☐ Collaborate with physicians and mental health professionals as indicated
  - Your dietitian should provide recommendations to other health care providers, such as rechecking celiac disease antibodies and other lab data, and need for evaluation of bone density and mental health status.

# 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

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| ☐ Confirm understanding of the gluten-free diet | Your dietitian should: (1) clarify questions of foods and ingredients allowed or to avoid, (2) clarify questions of preventing cross-contact with gluten in food preparation, (3) confirm age-appropriate proficiency at label-reading for foods and supplements. |
| ☐ Evaluate nutritional adequacy of child's gluten-free diet | Your dietitian should confirm understanding of caloric and nutritional needs. |
| ☐ Confirm understanding of bone-health needs | Your dietitian should: (1) confirm age-appropriate intake of calcium and vitamin D, (2) confirm understanding of the need for exercise to promote bone health. |
| ☐ Collaborate with physicians and mental health professionals as indicated | Your dietitian should provide recommendations to other health care providers, such as rechecking celiac disease antibodies and other lab data, and need for evaluation of bone density and mental health status. |
| ☐ Evaluate compliance with the gluten-free diet | Your dietitian should: (1) discuss barriers to compliance with the gluten-free diet, (2) build upon previous behavioral goals for improving compliance with the gluten-free diet. |
| ☐ Evaluate changes in growth measurements (height, weight, head circumference, etc.) | Your dietitian should provide appropriate dietary interventions for normalizing child's growth curve. |
| ☐ Evaluate any changes in nutrition-related labs | Your dietitian should: (1) confirm understanding of age-appropriate multi-vitamin needs, (2) make adjustments to micronutrient supplemental needs as required. |