A Resource for Health Care Professionals: Follow-up Management of Patients with Celiac Disease

Celiac disease (CD) is a serious disorder that requires careful management and follow-up. The gluten-free diet (GFD) should not be started before celiac disease is diagnosed by positive serology and histology. This resource will assist primary care physicians to provide long-term patient care. These recommendations may be modified according to individual patient needs.

Six key elements for management of patients with celiac disease

(Adapted from NIH 2004)

1. **Consult a dietitian skilled in the management of celiac disease**
   - Nutritional assessment, nutrient deficiency treatment & education re: food labelling, nutrient content of GFD, menu & food preparation, cross-contamination, dining out, etc.
   - The GFD is costly, complex and challenging. Without proper education and support, patients are at higher risk of complications (i.e., osteoporosis, infertility, gastrointestinal cancers, lymphoma, nutrient deficiencies, etc.) and excessive weight gain.
   - Strict avoidance of ALL sources of wheat, rye and barley (and cross-contamination).

2. **Educate about the disease and family testing**
   - Celiac disease, unlike other gluten related disorders, is a multi-systemic, malabsorptive, autoimmunedisease with an increased prevalence of associated conditions.
   - First degree relatives have a 10-15% chance of having or developing CD.
   - For steps for screening for CD see: www.celiac.ca/pdfs/blood%20test-rev.pdf

3. **Lifelong adherence to a strict gluten-free diet and evaluation of compliance**
   - Ingestion of as little as 50 mg of gluten (1/60 of a slice of bread) may damage the intestine.
   - Better adherence to a GFD is seen where there is a clear diagnosis, ongoing medical follow up and support by patient advocacy organizations, such as the Canadian Celiac Association (CCA).
   - Registered dietitian to provide timely education through initial individual or group settings and further followup as needed.
   - Refer to gluten-free diet compliance score. www.celiac.ca/dietarycompliance

4. **Identification and treatment of nutritional deficiencies**
   - Most patients benefit from a multivitamin supplement initially after diagnosis; ensure thatsupplement formulation is gluten-free.
   - Daily vitamin D and Calcium intake through foods and/or supplements (individualized and discussedwith dietitian).

5. **Access to an advocacy group (e.g. Canadian Celiac Association & local chapter)**
   - www.celiac.ca

6. **Continuous long-term follow-up by health professionals with expertise in celiac disease**
   - In the vast majority of patients, symptoms begin to improve within a month of starting a strict GFD.
   - Patients are at risk of developing other autoimmune disorders such as thyroid disease.

Guidelines for Family Physicians for Following Patients with Celiac Disease

Management	At diagnosis	At 3 months	At 6 months	At 1 year	Annual	Symptom recurrence
Measure weight and BMI	Yes	Yes	Yes	Yes	Yes	Yes
Measure growth (child)	Yes	Yes	Yes	Yes	Yes	Yes
History and physical exam	Yes	Yes	Yes	Yes	Yes	Yes
Education re: gluten-free diet (GFD)	Yes	Yes	Yes	Yes	Yes	Yes
Refer to registered dietitian (RD) with expertise in GFD	Yes	Yes	By request	By request	Yes (Ideal)	Yes
Suggest CCA membership	Yes					Yes
Screen for nutrient deficiencies (1)	Yes		If previously abnormal	If previously abnormal	If previously abnormal	Yes
Celiac serology (TTGA, DGPA or EMA)	If not already done		Yes	Yes	Yes *(2)*	Yes
Serum ALT, AST, ALP, GGT	Yes		If previously abnormal	If previously abnormal	If previously abnormal	Yes
Serum TSH	Yes				Every 2 years	
Bone density measurement	If signs of metabolic bone disease *(3)*, severe malabsorption, or other risk factors for osteoporosis			In some adults *(4)*	If previously abnormal every 2 years	
Re-refer to gastroenterologist						Abnormal serology or symptoms after RD review (5)

(1) *Tests include CBC, iron studies or ferritin, folate, calcium, albumin, phosphate, ALP, vitamin D and vitamin B12 as appropriate for each patient.*

(2) *Although the serological tests are not robust enough to detect minor dietary indiscretions, a positive test is very suggestive of ongoing gluten exposure; repeat every 1-2 years*

(3) *Premature osteoporosis, fracture with mild trauma with follow-up every 1-2 years until recovery.*

(4) *Peri- or postmenopausal women and men >50 yr of age or non-response to GFD at any age. If bone density measurement abnormal, repeat every 1-2 years until recovery .An abnormal bone density measurement in the GFD non-adherent patient may strengthen the argument fordietary compliance.*

(5) *Non-responsive celiac disease:*

- *Failure to respond to 6-12 months of GFD or re-emergence of symptoms/laboratory abnormalities while on aGFD*
- *Most common cause: intentional or accidental gluten exposure in the diet; ingestion of hidden gluten can come from a variety of unexpected sources*
- *Consider concurrent irritable bowel syndrome (IBS), primary or secondary lactose intolerance, FODMAP intolerances, small intestinal bacterial overgrowth, microscopic colitis, secondaay pancreatic insufficiency, eating disorders, food allergies, inflammatory bowel disease, gastroparesis, peptic ulcer disease & refractory celiac disease*
- *Repeat endoscopy with special evaluation of small intestinal biopsy may be indicated*

GFD = gluten-free diet, CBC = complete blood count, ALP = alkaline phosphotase, TTGA = tissue transglutaminase antibody, DGPA = deamidated gliadin peptide antibody,, EMA = endomysial antibody, TSH = thyroid stimulating hormone

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