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, autoimmune disease 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](http://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](http://www.celiac.ca/dietarycompliance)

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

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

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

(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 followup 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 for dietary 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 lactase intolerance, FODMAP intolerances, small intestinal bacterial overgrowth, microscopic colitis, secondary 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 phosphatase, TTGA = tissue transglutaminase antibody, DGPA = deamidated gliadin peptide antibody, EMA = endomysial antibody, TSH = thyroid stimulating hormone

Primary authors: Drs. Jenni Zelin, J. DeckerButzner, and RD Joyce Schnetzler

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Professional Advisory Council, Canadian Celiac Association

[cca logo]