


Checklist for managing patients with coeliac disease

Coeliac disease affects approximately 1 in 100 people and a diagnosis can be made at any age. The diagnosis is most often made in adults between the ages of 40 and 45 years, however, coeliac disease is often unrecognised as symptoms can be vague and non-specific and are not always related to the gastrointestinal tract. Laboratory investigations are the first step in making a diagnosis, which may then be confirmed with duodenal biopsy if required. Coeliac disease is a lifelong condition and strict adherence to a gluten-free diet usually results in complete resolution of symptoms and prevents further damage to the small intestinal mucosa. This in turn reduces the risk of long-term adverse health outcomes.

Coeliac New Zealand Incorporated is a not-for-profit organisation that aims to support children and adults who have been diagnosed with coeliac disease. It has developed a quick checklist designed for primary care clinicians to rapidly refresh their knowledge on the key points regarding this condition.

Coeliac New Zealand primary care checklist for coeliac disease:

1. **What to do if coeliac disease is suspected** – advise the person to continue with a gluten-containing diet and request laboratory testing for coeliac specific antibodies (usually written as “coeliac screen” on most laboratory forms).
2. **When should a person stop consuming gluten?** A person needs to be consuming gluten or to go onto a gluten challenge for eight weeks prior to diagnosis to ensure a correct diagnosis. Do not advise that gluten is excluded from the diet until there has been a confirmed diagnosis.
3. **When should a patient with coeliac disease be referred to a dietitian?** As soon as possible, after diagnosis. Check HealthPathways for access criteria for dietitian services. In most areas this will be through your local PHO, although children may meet the criteria for Te Whatu Ora funded dietitian services. While waiting to see a dietitian, recommend that patients or their parents/caregivers join local support groups and register with Coeliac New Zealand for education about a gluten free diet.
4. **Do people outgrow coeliac disease?** No, coeliac disease is a lifelong condition which if untreated is associated with an increased risk of long-term health problems, e.g. osteoporosis, infertility, lymphoproliferative disorders (e.g. T-cell lymphoma) and gastrointestinal malignancy.
5. **What is the treatment for coeliac disease?** There is no cure for coeliac disease, however, risks usually reduce following a permanent, strict, lifelong, varied and healthy gluten-free diet after diagnosis.
6. **Can patients have a “diet holiday” and consume gluten again?** The short answer is no. While it may be tempting for a person with coeliac disease to eat gluten if food choices are limited, or difficult to access, e.g. while travelling, consuming even a small amount of gluten can result in gastrointestinal damage. Many people with coeliac disease who inadvertently consume gluten will have a range of unpleasant symptoms (both gastrointestinal and other, e.g. aches, brain fog, fatigue), some are “silent coeliacs” who have no obvious symptoms post-exposure, but the gastrointestinal consequences are the same.
7. **Who should you test for Coeliac Disease?**
 - a. Symptomatic adults with any of the following: unexplained weight loss, anaemia, osteoporosis, nausea and vomiting, neurological issues, fatigue weakness and lethargy, ulcerations and/or swelling of mouth and tongue, skin rashes, irritable bowel symptoms and infertility.
 - b. Symptomatic children with any of the following: A bloated stomach, diarrhoea and/or constipation, general tummy upsets and/or vomiting, tiredness or lack of stamina, anaemia, poor growth or physical development, failure to thrive, difficulty in concentrating at home or at school, poorly calcified teeth.
 - c. First-degree relatives of a person with confirmed coeliac disease

 Further information for both patients and clinicians can be found on the Coeliac New Zealand website: coeliac.org.nz

 Other useful resources:

- Coeliac disease diet guide 2024
- Management guidelines for coeliac disease
- Paediatric pathway for coeliac disease
- Adult pathway for coeliac disease

