



**TILLY LOVES
NUTRITION**
BALANCE IS EVERYTHING

Follow-Up And Monitoring After Diagnosis (2026 Update)

**A clear, supportive guide to what happens after diagnosis and how
your health is monitored.**



Based on the 2026 British Society of Gastroenterology guidelines.

Why Follow-Up Matters

Follow-up ensures:

- Your symptoms improve
- Nutrient deficiencies resolve
- Your gluten-free diet is working
- Your long-term health is protected
- You receive the right support at the right time

This guide combines NICE and 2026 BSG recommendations.

1. First 2 Years of Follow-Up

All adults diagnosed with coeliac disease should receive regular follow-up for 2 years.

Appointments usually check:

- Symptoms
- Diet adherence
- Nutrient levels
- Bone health
- Emotional wellbeing
- Practical challenges
- Any accidental gluten exposure

2. Nutrient Monitoring

At diagnosis and during follow-up, doctors should check:

- Iron
- Folate
- Vitamin B12
- Vitamin D
- Calcium
- Thyroid function (autoimmune conditions often cluster)

Supplements are recommended only when needed.

3. DXA Scan (Bone Health)

Bone health is important because untreated coeliac disease can affect bone strength.

DXA scan at 1 year

All adults should have a DXA scan one year after starting a gluten-free diet.

Repeat DXA

A repeat scan is recommended:

- after 2–3 years
- if villous atrophy persists
- or if refractory coeliac disease is suspected

4. Pneumococcal Vaccination

All adults diagnosed with coeliac disease should receive a pneumococcal vaccination.

Booster

A booster is recommended after 5 years if:

- you have refractory coeliac disease
- you take long-term immunosuppressive medication

5. Assessing Gluten-Free Diet Adherence

No single test can confirm adherence, a combined approach is recommended:

- Symptom review
- Diet review with a specialist
- Serology
- Follow-up biopsy (only when needed)
- Discussion of challenges and barriers

6. After 2 Years

If you are stable and doing well:

You may move to patient-initiated follow-up (PIFU)

This means you contact your team when you need support.

Ongoing follow-up is needed if:

- symptoms persist
- nutrient deficiencies continue
- adherence is difficult
- complications develop
- villous atrophy persists

7. When to Seek Specialist Review

You should be referred back to specialist care if:

- symptoms do not improve
- nutrient deficiencies persist
- bone health worsens
- biopsy shows ongoing villous atrophy
- refractory coeliac disease is suspected
- new symptoms develop

8. Refractory Coeliac Disease (Short Overview)

This is rare and only diagnosed in specialist centres.

RCD1

- Treated with open-capsule budesonide
- Strict gluten-free diet continues

RCD2

- Requires specialist MDT care
- Flow cytometry is needed for diagnosis
- Imaging may be required

9. Support and Signposting

You should be signposted to:

- Coeliac UK
- Local support groups
- Online communities
- Your GP
- Specialist dietitian
- Specialist gastroenterology services if symptoms persist

10. For Practical Gluten-Free Living

See the separate guide:

Newly Diagnosed with Coeliac Disease (Your calm, sensory-friendly, practical guide.)