NAVIGATING DIAGNOSIS

ADJUSTING TO LIFE WITH COELIAC DISEASE

When someone is diagnosed with coeliac disease, it can be a big adjustment – not just physically, but emotionally and socially too. Here are some of the range of emotions that can occur and how you reframe your way to empowerment.

BY SIMON KNOWLES

The journey to a coeliac disease diagnosis is not the same for everyone. For some, it follows a long history of unexplained and frustrating symptoms which, once diagnosed, can bring both understanding and relief. For others, the diagnosis comes as a surprise, often prompted not by gastrointestinal symptoms but by persistent fatigue or abnormal blood test results, such as low iron levels. For many, however, diagnosis is preceded by ongoing gastrointestinal issues, sometimes accompanied by a known family history of coeliac disease.

Personal narrative

What is clear is that each individual's journey to a coeliac disease diagnosis is deeply personal, shaped by the nature of their symptoms, the awareness of healthcare providers, and the presence – or absence – of known risk factors. Like any health-related experience, a diagnosis can evoke a wide range of thoughts and emotions such as anger, anxiety, relief, sadness, frustration, confusion, and grief, as individuals come to terms with what the diagnosis means for their health, lifestyle, and future.

Relief – then anxiety

Many individuals report a combination of relief and anxiety upon receiving a coeliac disease diagnosis. Relief often stems from finally having an explanation for long-standing or unexplained symptoms. However, diagnosis can also be unexpected. Many people are diagnosed without experiencing classic symptoms, leading to disbelief and confusion.

A 2019 UK-based study, *The impact of diagnosis on health-related quality of life in people with coeliac disease,* by Mara Violato and Alastair Gray, involving over 1500 participants, found 65 per cent of respondents reported experiencing at least four distinct symptoms prior to diagnosis, with the average duration of symptoms lasting 12.8 years. While diagnosis may bring clarity, it is frequently accompanied by immediate anxiety about the unknowns of managing the condition and feeling overwhelmed by the implications of lifelong dietary change.

Sense of loss

A sense of loss is also common, particularly for those with deep cultural or emotional ties to food. The diagnosis often means more than just eliminating gluten – it may require changing familiar routines, comfort foods, and shared social experiences. Individuals often become more acutely aware of the central role food plays in social settings. It is not uncommon for people to report, post-diagnosis, a feeling of losing spontaneity, convenience, and aspects of their social and cultural life. The initial experience of living with a gluten-free diet may result in missing out on shared meals, traditions, and travel experiences, leading to feelings of exclusion and grief. This can also impact one's sense of identity (as found by Catharine Rose, Gary U Law and Ruth A Howard in *The psychosocial experiences of adults diagnosed with coeliac disease: A qualitative evidence synthesis)*. For some, their identity becomes singularly defined by the diagnosis, rather than recognising they are a multifaceted individual who happens to have coeliac disease.

Pressure cooker

This shift reflects the need to rethink and actively engage with dietary habits previously taken for granted. Individuals may put unnecessary pressure on themselves to make immediate and significant changes to their lifestyle, such as purchasing new kitchen appliances to avoid cross-contamination, changing shopping habits, and reconsidering how they participate in social eating.

From the moment of diagnosis, a frequent concern becomes ongoing risk of accidental gluten exposure. This abrupt transition can be disorienting, especially when faced with the personal expectation to make significant changes quickly.

The impact of this change extends beyond the individual diagnosed. It can also bring emotional stress and disruption to those they live with and socialise with, as household routines, shared meals, and social interactions may need to be restructured. Partners, family members, and friends often find themselves adjusting their own behaviours and expectations, which can lead to feelings of frustration, guilt, or helplessness. These ripple effects highlight the broader social and emotional dimensions of a coeliac disease diagnosis.

Way to empowerment

Yet it is equally important to recognise that it can also mark a turning point for positive change. Engaging with a gluten-free diet following diagnosis can help alleviate often debilitating physical and mental health symptoms. For many, the diagnosis provides a sense of clarity and control over what may have been a confusing and prolonged experience of unexplained symptoms.

This renewed sense of agency can be empowering, allowing individuals to take proactive steps towards improving their wellbeing. Rather than continuing to navigate uncertainty, the diagnosis offers a framework for understanding their health and making informed choices that support long-term physical and emotional resilience.

There are several psychological strategies that can help people cope with the changes and challenges:

- One of the most important things is learning to **advocate for yourself**. This means feeling confident to speak up about your dietary needs, especially when eating out or attending social events. It might feel awkward at first, but being clear helps protect your health and builds self-assurance over time.
- It's also helpful to **be kind to yourself**. Feeling overwhelmed, frustrated or even a bit lost after a diagnosis is normal. Practising self-compassion, and reminding yourself you're doing your best and that it's okay to have tough days, can ease some of that emotional pressure.
- **Connecting with others** is another powerful tool. Whether it's friends, family, or a support group, sharing your experiences can help you feel less alone and more understood. It's comforting to know others are going through similar things.
- **Accepting the diagnosis** is a key step in moving forward. Acceptance doesn't mean you have to like the situation, but it does mean acknowledging it and finding ways to adapt. This mindset can reduce stress and help you focus on what you can control. When things go wrong, such as accidentally eating gluten, it's easy to feel upset or blame yourself or others. Instead, try to focus on solutions.. Ask yourself what you can learn from the situation and how to avoid it in the future.
- **Remember and reconnect with your values** – you are not defined solely by your coeliac disease diagnosis. You are, and will always be, more than a medical label. While the diagnosis may shape aspects of your daily life, it does not diminish your identity, strengths, or your capacity to thrive. Holding onto what matters most to you – your relationships, passions, and goals – can help anchor you through the changes and remind you that you are a whole person, not just someone with coeliac disease.
- **Stress-reduction techniques like meditation, deep breathing, or gentle yoga can also be helpful**. These practices can calm the mind, reduce anxiety, and help you feel more grounded during times of change.
- Finally, **don't hesitate to seek professional support**. Talking to a mental health professional, such as a psychologist, and especially someone experienced with chronic health conditions, can provide valuable tools for managing your emotions, building resilience, and provide further ways of helping you adjust to life lived with coeliac disease.

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