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ADHERENCE TO A GLUTEN-FREE DIET IN ADULT COELIAC DISEASE

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A strict gluten-free diet for life is the only effective treatment for coeliac disease (CD). Despite the proven efficacy of the gluten-free diet (GFD) in eliminating symptoms and normalising mortality rates, as many as 58 percent of adults with CD may not adhere to treatment (1). Research has identified a number of factors associated with adherence to a GFD.

COELIAC DISEASE

Coeliac disease (CD) is a gluten-induced autoimmune disease found in genetically susceptible individuals with a prevalence of around one percent. This condition is characterised by chronic inflammation in the proximal small intestinal mucosa and most patients have some degree of villous atrophy. Impaired nutrient absorption, diarrhoea, steatorrhoea, abdominal pain and iron deficiency anaemia are common in CD. Patients are also prone to extraintestinal manifestations, including psychological disorders, infertility, malignancy, other autoimmune diseases and osteoporosis. Complete removal of gluten from the diet should result in symptomatic, serologic and histologic remission and the normalisation of mortality rates.

THE GLUTEN-FREE DIET

The clinical efficacy of the GFD in treating CD has been well documented and this is currently the only accepted treatment. Gluten is the general term for the storage proteins in wheat (gliadin), rye (secalin) and barley (hordein). As gluten-containing products (such as bread, breakfast cereals, pasta, beer, cakes and biscuits) are widely consumed in the UK, adopting a GFD can involve a drastic change to normal dietary habits and the GFD can be restrictive (2).

Gluten-free (GF) products can be broken down into two categories: Naturally occurring GF products and GF substitutes. Most meats, dairy products, fruit, vegetables and rice are naturally GF. Substitute GF products, in which GF ingredients are used in place of wheat, rye or barley, are available in the 'free from' aisles of supermarkets, healthfood stores, on the internet and on prescription (with a prescription charge). In recent years, the range, availability and quality of GF substitutes has improved, but they are usually significantly more expensive than their gluten-containing counterparts (3).

Patients with CD have to be cautious to avoid gluten when shopping, cooking and eating out. GF food can become contaminated with gluten during preparation and gluten is often 'used' where it may not be expected, such as food coatings and sauces. Although oats are generally tolerated, a few patients do suffer from an adverse reaction to oats. Oats are frequently harvested and milled alongside wheat and the risk of contamination is high. Only oats labelled as 'gluten-free' are recommended for people with CD.

Although the term 'gluten-free' on food labels implies that no gluten is present, this is not necessarily the case. Under new EU regulations, products that contain less than 20 parts per million (ppm) of gluten are allowed to be labelled 'gluten-free'. Specialist products containing less than 100ppm of gluten can be labelled as 'very low gluten'. Most people with CD can tolerate these products, however, some people cannot tolerate even tiny amounts of gluten and these products may be not be suitable.

Establishing which products are acceptable for a GFD can be complicated. Ingredients lists on food packaging can be confusing and not all products that are free from gluten are labelled 'gluten-free'. Coeliac UK, publishes an annual food and drink directory, listing GF products available in the UK and this can be a valuable resource when planning and shopping for GF food.

ADHERENCE TO TREATMENT

The term 'adherence' is defined as: 'the extent to which the patient's behaviour matches agreed recommendations from the prescriber' (4).

Helen is a PhD student with a background in nutrition. She is currently researching the factors affecting adherence to a gluten-free diet in adults with coeliac disease using a research method called concept mapping.

Table 1 Summary of the key findings from studies of adherence to a GFD in adults with CD reported in a systematic review by Hall et al (1)

Author	Year	Country	Number of participants	Factors associated with adherence
Addolorato et al	2004	Italy	66	Psychological support was found to reduce depression and this was linked with better adherence.
Butterworth et al	2004	UK	87	Coeliac UK membership, better understanding of GF food labelling, obtaining sufficient GF food and regular dietetic follow-up were associated with better adherence in Caucasians. These factors were not associated with adherence in South Asians who were less likely to be members of Coeliac UK.
Casellas et al	2006	Spain	73	40 percent of participants reported difficulty finding GFF and 50.8% reported difficulty understanding food labels. Age was not related to adherence.
Goggins et al	1995	UK	91	Cost, difficulties with social occasions and problems finding GF food were reported to make adherence difficult.
Gremigni et al	2006	Italy	128	Males were less compliant than females. The experience of illness was found to be associated with adherence.
Hogberg et al	2003	Sweden	29	At least 80 percent of patients diagnosed before the age of four years were adherent, compared with just 36 percent adherence in those aged over four years at diagnosis.
Kokkenen et al	1998	Finland	42	Age at diagnosis, education and social class were not associated with adherence. Knowledge of CD and the GFD were associated with better adherence.
Lamontagne et al	2001	Canada	234	Younger participants and those living in larger cities found adherence to be difficult. Those who reported concern about preparing meals found it difficult to adhere. Social worries and frequency of eating out were related to difficulties in adherence.
Leffler et al	2007	USA	154	Factors associated with adherence included: understanding the GFD; membership of a coeliac support group; perceived ability to adhere to a GFD despite travel, mood or stress; the presence of other food intolerances; concern about the cost of GF products; and concern with gluten exposure. Age and gender were not associated with adherence.
Viljamma et al	2005	Finland		Adherence was found to be similar in screen-detected and symptom-detected patients with CD.

Patients with CD are advised to follow a strict GFD for life. This can be very challenging and a systematic review by Hall et al (1) found that non-adherence may be as high as 58 percent in adults with CD. Patients who do not adhere to a GFD risk developing serious health problems, such as osteoporosis and small bowel cancer (5). Intestinal lymphoma has been reported in 10 to 15 percent of patients with CD who are non-adherent with treatment (6).

Evidence about the factors affecting adherence to a GFD in adults has been reported in a small number of studies. Table 1 (overleaf) provides a summary of some of the key findings from studies as reported in a systematic review by Hall et al (1).

Some of the findings from the studies in Table 1 are contradictory. This may be due to cultural differences and differences in the method of assessing and defining adherence. One study reported higher adherence in patients diagnosed at a younger age while another study reported no association between age at diagnosis and adherence. Conflicting evidence also exists on the relationship between gender and adherence.

Membership of coeliac support groups has been associated with better adherence to a GFD and patients are advised to join Coeliac UK at diagnosis. Coeliac UK provides information on many aspects of CD and the GFD and members are sent a copy of Coeliac UK's annual GF food and drink directory. Local Coeliac UK groups provide social support for members and this is believed to be a good source of motivation when following a GFD.

As GF food is a niche market, it tends to be expensive and less readily available than gluten-containing products. Hourigan argues that the increased cost of GF products is addressed by the provision of GF food on prescription in the UK. The role of prescribed GF products is to ensure patients have equal access to affordable staple foods, such as bread and flour and this provision has been associated with improved adherence to a GFD. In the UK, GF food has become more widely available in recent years. This may be due to advances in technology, increased anxiety over-gluten consumption and a more responsive food industry which is keen to develop products for this niche market.

There remains a lack of understanding about the factors affecting adherence to a GFD in adults with CD. Up to 58 percent of adult patients risk developing serious health problems by not adhering to a GFD and further research is needed.

THE ROLE OF THE DIETITIAN

The British Society of Gastroenterology recommends the long-term follow-up of patients with CD (7). Patients receiving regular follow-up are usually better at adhering to a GFD. Evidence suggests that the best care for patients with CD is a dietitian-led coeliac clinic which patients attend annually. The role of the dietitian is not only to encourage people with CD to adhere to treatment, but also to ensure the GFD provides the correct balance of nutrients.

Dietitians can provide practical information to support patients, such as offering advice on meal planning and preparation. They need to be skilled in behavioural change strategies and motivational techniques. Patients who experience mild symptoms, or are asymptomatic, may require more motivation to follow a GFD than symptomatic patients who may be motivated by the elimination of symptoms. Patients need to be reminded of the importance of following a gluten-free diet in reducing the risk of developing serious health problems.

Patient education is important for achieving dietary adherence. Patients have access to a wide range of literature about the GFD, much of which is contradictory and of variable quality. It is important that dietitians are appropriately trained to provide the most up-to-date and consistent advice to patients at diagnosis and during follow-up. The provision of information about the GFD is essential for self-management. Behavioural change strategies and motivational techniques are also important tools for the dietitian. The value of being a member of a coeliac support group cannot be over emphasised and dietitians should encourage patients to join Coeliac UK soon after diagnosis. This charitable organisation provides members with tips and advice on dealing with the day-to-day management of CD as well as providing a sense of community through social networking. This can provide a source of motivation and education in addition to the support and advice provided by dietitians.

SUMMARY

Unmanaged CD is linked to an increased risk of serious health problems. Up to 58 percent of adults with CD do not adhere to a GFD. The role of the dietitian is pivotal for the successful management of CD. Membership of a coeliac support group is also useful for motivating patients and educating them about the GFD. Studies have identified several barriers to adherence, however, the findings are inconclusive and further research is needed to gain a better understanding of the factors affecting adherence to a GFD.

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Questions relating to: *Adherence to a gluten-free diet in adult coeliac disease*
Type your answers below and then **print for your records.** Alternatively print and complete answers by hand.

Q.1	What are the common symptoms of coeliac disease?
A	
Q.2	What is the result of removing gluten from the diet of a CD patient?
A	
Q.3	What is gluten and in which foods can it be found?
A	
Q.4	Gluten-free products can be broken down into which two categories?
A	
Q.5	What are the current EU regulations on labelling gluten-free products?
A	
Q.6	What is defined as 'adherence' to treatment of CD?
A	
Q.7	What are the risks of non-adherence to treatment?
A	
Q.8	What is the role of a dietitian in the care of a CD patient?
A	

Please type extra notes here . . .