Managing & Supporting Adherence to a Gluten-free Diet

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Coeliac disease (CD) affects 1% of the population in the UK and the only treatment is strict adherence to a lifelong gluten-free (GF) diet.[1] It takes an average of 13 years from onset of symptoms to achieve diagnosis and, therefore, it is essential that we continue to improve awareness of this condition. The work of Coeliac UK – a leading charity who provide support, create awareness and strive to improve diagnosis of this condition – should also be promoted.

Evidence has shown that of those patients who are symptomatic, approximately 30-50% do not strictly comply with a GF diet.[2] Compliance is essential for those with CD to prevent the development of health complications, such as nutritional deficiencies, osteoporosis, fertility difficulties, as well as malignancy.[3] Compliance to a GF diet is multifactorial and can be affected by many demographics, including age, ethnicity and income.[2] The cost of non-compliance can have a clear impact on the health of the individual.

Dietitians play an essential role in the management of patients who have been diagnosed with CD. The role extends from the education of those newly diagnosed with the condition, to managing and supporting patient adherence to a lifelong GF diet. In order to do this successfully, we need to recognise what exactly affects compliance to enable us to focus our attention and provide the support where it is most needed.[4]

Management of patients diagnosed with CD varies throughout the UK. Some patients will receive education in a group setting, while some are educated on a one-to-one basis. Some patients will be reviewed annually by a dietitian, while others are discharged after an initial consultation. The care provided may vary depending on resources available to the dietetic department, including time and staffing levels.

This article will focus on the current guidelines for managing and supporting patients with CD and will identify how we can improve compliance of the GF diet, especially with individuals where research has shown it is less likely.

Initial dietetic consultation

Newly diagnosed patients should be referred to a dietitian to discuss dietary management.[5]

The National Institute for Health and Care Excellence (NICE) guidance – Coeliac disease: recognition, assessment and management – states: '*A healthcare professional with specialist knowledge of coeliac disease should tell people with a confirmed diagnosis of coeliac disease about the importance of a gluten free diet and give them information to help them follow it. This should include:*

- *Information on which types of food contain gluten and suitable alternatives, including gluten free substitutes*
- *Explanations of food labelling*
- *Information sources about gluten free diets, recipe ideas and cookbooks*
- *How to manage social situations, eating out and travelling away from home, including travel abroad*
- *Avoiding cross contamination in the home and minimising the risk of accidental gluten intake when eating out*
- *The role of national and local coeliac support groups.*'[6]

Other factors that should be discussed at this initial consultation include:

- The importance of ensuring sufficient intake of nutrients, including calcium, iron and vitamin D in a GF diet[7]
- Whether GF foods are available on prescription in your area.

Adherence to a GF diet is better achieved when the patient is well-educated and supported by carers and families.[8, 9] It is vital that the information we provide is clear and that we recognise any issues with literacy and understanding, so we can support the patient's individual needs – e.g. providing written information in larger fonts and in braille for those who are visually impaired, providing translators when required, or, simply, encouraging patients to bring a family member with them to consultations.

Understanding food labelling

All patients with CD should have a good understanding of food labelling. Muhammad *et al.* found that those with an understanding of food labelling were more likely to adhere to a GF diet.[10]

A number of studies have highlighted difficulties interpreting food labels as a reason for non-compliance, particularly in the adolescent population.[11] Muhammad *et al.*[10] found that a higher proportion of South Asian patients reported difficulties following the GF diet, compared with caucasians, due to a lack of understanding of food labels.

As healthcare professionals, it is important that we provide patients with the skills to read food labels and assess their understanding as much as possible.

Social situations & travel

Studies show that compliance can be affected when patients are in social situations, such as eating out and socialising with friends. The Barratt *et al.* study[2] identified this as a reason for non-compliance in the adolescent population. This is especially important when we take into account how age is associated with dietary compliance: 4% of those under 35 reported full adherence to a GF diet and 12% of the under 35 group reported partial adherence in the same study.

We can support patient compliance by providing practical information on local eateries catering for patients on a GF diet and providing details on online resources available from Coeliac UK, such the 'Eating out Venue Guide', travel guides and Coeliac UK App.

The role of national & local support groups

Coeliac UK is a support network for patients with CD and provides relevant resources, webinars and links to support compliance to a GF diet. It can prove helpful for patients who have been diagnosed with CD but have not yet been seen by a healthcare professional. The guidelines are clear that joining a national coeliac support group can help patients cope with their disease and all patients should be encouraged to do so.[8, 9]

Local support groups can be particularly useful, providing patients with information on local suppliers and offering guidance on eating out safely in the local community. Membership can allow for exposure to others with CD, and can improve the lives of many people with CD and as a result, improving GF dietary adherence.[4]

Foods available on prescription

Despite GF foods being more readily available today, they are still not fully accessible across the UK, making it more difficult for the elderly and those living in rural areas to obtain a supply. GF foods are often more expensive than the equivalent wheat-based products[12, 13] and being unable to afford GF foods has been linked to lower adherence of the diet.[13]

Evidence has shown that patients are more likely to adhere to a GF diet when receiving foods on prescription[10, 14] but unfortunately there have been restrictions to these prescriptions in England since 2015 with some areas having no access to GF foods on prescription at all.

If foods are available on prescription in our local area, we should make patients aware of this in the dietetic consultation and educate them on how they can use this service. In areas where foods are no longer available on prescription, we can support patient adherence by encouraging them to use online shopping, provide guidance and recipes to allow them to cook from home without the need for specialist products, and we can provide resources from Coeliac UK, e.g. the 'Gluten Free on a Budget' booklet.

Follow up appointments

One of the key factors relating to adherence is dietetic input and regular follow-up, and continued *'maintenance of motivation'*[8] and has been found to improve adherence by up to 97.5%.[15] As stated previously, follow up is something that varies greatly throughout the UK. Patients can be followed up in the hospital setting by gastroenterologists and dietitians, or in primary care by GPs and pharmacists.

Although annual dietetic reviews would be considered as 'gold standard', NICE recognises that this is not always possible due to limited resources and recommends that patients are re-referred to a dietitian if there are any concerns with a patient adhering to a GF diet.[6]

If dietetic follow up is not available, we must ensure that patients have support in the community to allow them to adhere to a GF diet. We should encourage them to join support groups, and refer back to primary care to request annual follow up.

We must also recognise the importance of family support in order to encourage adherence to a GF diet in the long-term. The British Society of Gastroenterology[8] and NICE guidance[6] supports family member attendance at dietetic consultations. Although studies of family support with CD are limited, when studying diabetes, another condition where patients are often required to make long-term dietary changes, Singh *et al.* identified the importance of having family support.[12]

Conclusion

Despite the improved availability and quality of GF foods on the market and the increased awareness of CD, compliance continues to be an issue. Our role as dietitians is essential to educate, motivate and support our patients to the best of our ability.

Follow up of patients with CD plays a vital role in managing and supporting patient compliance to a GF diet but, due to a lack of resources, many departments are unable to provide this service and rely on other healthcare professionals to take on this role.[16]

Further research is required to establish the most cost-effective way of delivering CD follow-up care.[16] Understanding and maximising the effectiveness of dietitians is another key research area identified by NICE which could help advance long-term care.[6]

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