

## MANAGING INCREASED DIAGNOSIS OF COELIAC DISEASE THROUGH GROUP EDUCATION



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Claire has been a Specialist Dietitian in Gastroenterology working for Gloucestershire Hospitals NHS Foundation Trust for over five years. She previously worked in the medical nutrition industry and also works part time in a freelance capacity. Her particular clinical areas of interest are coeliac disease and irritable bowel syndrome.

**With a one percent population prevalence in the UK (1) and similar levels seen across Europe, coeliac disease is one of the most common gastrointestinal conditions now seen. Successful management of the condition remains at present through the complete removal of gluten from the diet, a restriction that for some can be very difficult to accept and to follow (2). Management guidelines for adults with coeliac disease recommend long-term follow up care that can be provided via a dietetic-led coeliac clinic, with patients being counselled on diagnosis and with further follow-up ongoing (3).**

Evidence suggests that patients seen in a dietetic-led coeliac clinic have improved outcomes (4) and indeed that dietetic follow-up is the method for management that patients prefer (5). Dietitians are uniquely placed to provide both the detailed and specialised advice required to educate patients on the dietary changes required and also to empower patients to become experts in their condition, which is paramount to successful management through use of skills in behaviour change and motivational interviewing (6). Adherence to a gluten-free diet is vital but is a huge challenge for many (7), particularly for those who may be asymptomatic or only have mild symptoms. Patients who struggle to adhere to a gluten-free diet are at risk of developing significant long-term complications such as osteoporosis, ongoing symptoms and malabsorption of nutrients such as iron, folate and calcium, also intestinal lymphoma in a small number of cases. A very practical approach on issues such as specific food

choices, meal planning and preparation can therefore be hugely helpful.

### DIETETIC-LED CLINICS

We have run a dietetic-led coeliac clinic at Gloucestershire Hospitals NHS Foundation Trust since 2003,

with three clinics running per month across two hospital sites. Since the publication of NICE guidance on recognition and assessment of coeliac disease (8) (2009), we have seen a large (and welcome) rise in the diagnosis and referral rate across Gloucestershire. This had led to much longer wait-

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ing times for patients to be seen than was acceptable. However, with no further funding available for additional clinics to support the increases in referrals seen, an alternative approach was required.

Following discussions with colleagues in other trusts and with the support of our Gastroenterologists, I proposed a 90-minute group education session for newly diagnosed patients to replace one of

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Table 1: Dietetic-led management of coeliac disease patients in GHNHSFT

Stage of treatment	Detail	Responsibility
<b>Diagnosis</b>	<b>Confirm diagnosis by D<sub>2</sub> biopsy and supporting serology</b>	<b>Gastroenterologist</b>
<b>Management</b>	<p><b>3 appointments in specialist dietetic-led coeliac clinic:</b></p> <p><b>Appointment 1 group education session - 90 minutes (within one month of referral)</b></p> <p><b>Appointment 2 20-minute one-to-one f/up (3/12)</b></p> <p><b>Appointment 3 20-minute one-to-one f/up (6/12)</b></p> <p><b>Discharge to GP when stable/treated coeliac disease for annual review.</b></p>	Gastroenterology Specialist Dietitian
<b>Monitoring Annual review</b>	<ul style="list-style-type: none"> <li>• Monitor wt/BMI</li> <li>• Check bloods (FBC, folate, ferritin, vitamin B<sub>12</sub>, U&amp;Es, LFTs, TSH, Ca, TTG)</li> <li>• Review symptoms - bowels, GI symptoms, energy levels</li> <li>• Assess motivation towards adherence to GFD</li> <li>• Review GF food prescription</li> <li>• Assess need for further DEXA according to FRAX osteoporosis risk calculator</li> </ul>	GP
<b>Complications</b> Complex, unstable or untreated coeliac disease:	<ul style="list-style-type: none"> <li>• Unintentional wt loss (&gt;10% over 6m)</li> <li>• Abnormal bloods (e.g. low ferritin, vitamin B<sub>12</sub>, folate, +ve TTG)</li> <li>• Abnormal bowel symptoms with need to try dietary exclusions, e.g. lactose, malt extract, codex wheat starch exclusions</li> <li>• Complex dietary needs, e.g. restrictive diet, concern about nutritional inadequacy</li> <li>• Co-conditions requiring dietary assessment and advice, e.g. IBS, lactose intolerance, IBD, DH, T1/T2 diabetes mellitus, pregnancy</li> </ul>	GP / Consultant <b>Consider re-referral to Gastroenterology Specialist Dietitian as appropriate</b>

Table 2: Comments from patient evaluation following coeliac group education session - May 2012

“Very interactive and informative – very worthwhile.”

“It has made things clearer and I feel more confident to start.”

“I’d recommend the group - by being with others in the same situation, knowing you’re not dealing with it on your own.”

“I did quite a bit of research on the internet, but I found that the session with the dietitian gave me more of a clear understanding.”

“I’d recommend the group because it was informative and very friendly.”

“Really friendly relaxed atmosphere, interesting to listen to, very informative - thank you.”

our clinics. This would enable me to see up to 12 new patients each month, three to five more per month than with our previous clinic set up, and would provide more time than in a clinic slot to provide all the information needed for newly diagnosed patients. The group education sessions started in the summer of 2010. Therapeutic group education in aspects of nutrition is widely used with good outcomes in other long-term conditions, for example, diabetes, weight management and cardiac rehabilitation, though very little has been published to date on group education in coeliac disease. The two further clinics remain to review existing patients and to see those who were

felt not to be appropriate for group education and, in this format, nine patients could be seen within each clinic with 20 minutes for each patient (longer for a new patient at the end of the clinic if required).

**GROUP EDUCATION SESSIONS**

The protocol for management of our coeliac disease patients can be seen in Table 1. The group education session is where the condition and dietary management is introduced in detail, covering factors such as food labelling, hidden sources of gluten, cross contamination, eating away from home and tips for holidays, along with current guidance on the introduction of pure oats and barley malt extract. A healthy gluten-free diet and calcium and iron requirements are also discussed with practical advice on meeting these. Advice is also given on gluten-free prescribable foods and the current guidelines and practicalities for prescribing in Gloucestershire are discussed. Samples are provided from some of the main manufacturers to give out at the end of the sessions, along with starter cards to enable further samples to be delivered to the patients’ homes. On occasion, groups are also attended by a representative from one of the gluten-free manufacturers who will provide a

stand and additional information for patients, but a range of manufacturers are always represented at each group. The benefits of membership of a support group are also emphasised and patients are actively encouraged to join Coeliac UK for ongoing support and information. We are lucky in Gloucestershire to have an active local Coeliac UK group with various events occurring through the year, so these are always highlighted.

There is very much an emphasis of informality in the group setting - sharing experiences and asking lots of questions are very much encouraged throughout the session in order to maintain interest for the 90 minutes, as well as fostering an atmosphere of support and empathy, which again has been shown to result in increased patient satisfaction. Specific examples of feedback from our group education sessions can be seen in Table 2, and evaluations have shown that, in addition to the information provision, the social and emotional benefits of shared experience and tips are rated as equally important. Coeliac disease is one of the few conditions where sufferers are required to announce their condition in any social situation involving eating and this 'unwanted visibility' can present significant difficulty for some people to the extent that they may choose not to disclose their condition, and in some cases eat gluten containing foods when out (2). The group environment can present a positive focus and reduce isolation, acknowledging the social and psychological

elements of managing their diet as part of their daily life, along with sharing practical tips for restaurants and eateries in the local area that offer a good gluten-free service.

Following the group session, our patients are followed up three and nine months later in one-to-one consultations to provide further individualised dietary advice and support as needed. At present, the majority of our patients are discharged back to the care of their GP for long-term monitoring a year after diagnosis, due to limitations in capacity, but all GPs are aware that they have the option to re-refer their patients at any time should further advice be required (Table 1). A proposal to offer an annual drop in session with an educational component is currently being considered.

### CONCLUSION

The diagnosis rate of coeliac disease is increasing, but with limited financial resources to increase dietetic and clinical capacity, other approaches are required to ensure that patients receive the detailed dietary information and support they need to empower them to manage their condition in a timely manner. Our newly diagnosed coeliac education group has helped to manage our increased referral rate and, in addition, provides patients with empathic support and shared experience that they may not have previously received in a one-to-one appointment.

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**Questions relating to:** *Managing increased diagnosis of coeliac disease through group education.*

Type your answers below and then **print for your records**. Alternatively print and complete answers by hand.

Q.1	What is coeliac disease (CD)?
A	
Q.2	Briefly outline the dietitian's role in the nutrition management of patients with CD.
A	
Q.3	What are the complications for patients not adhering to a gluten-free diet?
A	
Q.4	What are the benefits of group education sessions to patients with long-term conditions such as CD?
A	
Q.5	Describe some of the benefits of shared-experience sessions to CD patients.
A	
Q.6	How have the group education sessions helped the coeliac-led clinics in Gloucestershire Hospitals NHS Trust?
A	
Q.7	What other proposals may be put forward to help manage increased diagnosis of CD?
A	

Please type additional notes here . . .