Nutritional Management of Coeliac Disease/ Dermatitis Herpetiformis Care Pathway (adults)

Appointment	Targets of Nutritional Intervention	Discharge Criteria
Initial Assessment 60-90* minutes *consider use of group sessions - unless exclusion criteria: poly diagnoses, communication barriers, patient requests individual assessment/ home visit needed	**Assessment:** • Obtain consent for assessment/treatment • Confirm appropriate referral - diagnosis confirmed via duodenal biopsy [a] and serology (tTGA and/or EMA)[1] or referral from a consultant gastroenterologist for a three month gluten-free trial due to equivocal results (e.g. genetic testing [b]-positive HLA typing in negative/Marsh 1 biopsy or symptomatic patients with positive serology and negative/Marsh 1 biopsy results). Diagnosis can be made by consultant if symptomatic improvement obtained • Determine understanding of diagnosis and gluten-free diet • Previous medical history • Social history e.g. Work environment, home environment, support network - family/friends, Preparation/provision of meals • Family history – advise that symptomatic first-degree relatives should undergo testing for coeliac disease[2,3] • Medications (All licensed medications are gluten free. The presence of the PL Number confirms gluten free.) • Document relevant available biochemistry to check on small intestinal absorption (full blood count, ferritin, serum folate, vitamin B12 and vitamin D), bone profile (calcium, alkaline phosphatase), associated autoimmune conditions (thyroid-stimulating hormone and thyroid hormone), electrolyte and liver profile • HbA1c, if has diabetes • DEXA scan bone density results if available • Previous and current symptoms (bowel habit, abdominal pain, bloating, tiredness, neurological symptoms e.g ataxia, neuropathy, headaches and atypical symptoms – e.g. low mood. Skin condition (in cases of Dermatitis Herpetiformis) should be noted • Weight (kg),weight history, height (m) and BMI • Diet history may be considered **Gluten-free dietary education:** • Coeliac disease, causes, symptoms and role of gluten-free diet using visual aids or prepared presentations e.g. Schar presentation;http://www.drschaer-institute.com/uk/useful-resources/toolkits-4635.html (updated Oct 2016). Coeliac UK are currently working on standardised presentation and this may be available in the near future (check www.coeliac.org.uk) • Lifelong treatment and rationale for gluten free diet – advise on need to reduce short (e.g.GI symptoms, anaemia etc) and long term complications (e.g osteoporosis, infertility, lymphoma)	

	• Naturally gluten free foods • Naturally occurring and hidden sources of gluten • Where to obtain gluten-free foods – discuss range available • Importance of combining healthy eating with gluten free diet (and consideration for any other dietary restrictions e.g. diabetes, vegetarian) • Consideration of calcium (at least 1000mg calcium per day)[2] and iron intake (and whether supplementation necessary) • Benefits of Coeliac UK membership including availability of Coeliac UK Food & Drink directory (and monthly updates)/Coeliac UK App/eFDD[4] • Gluten-free products available on prescription including prescribing guidance/allowance [4] • Food labelling, allergen information[4] • Cross-contamination including preparation and storage of food including education of family members/ domiciliary carers/ catering staff etc • Cooking methods • Eating out / holidays/ Communion (if appropriate) • Use of gluten-free Oats[c]. • Coeliac UK guidance on pneumococcal vaccine could be provided [3] **Provide relevant written information and contact details:** • Gluten-free diet sheet e.g. NDR; A guide to gluten free living • Prescribing guidelines and current prescribable list[4] • Company sample product requests • Coeliac UK membership form • Information on eating out, local information (eg Coeliac venue guide[4]) • Local support group details (Coeliac UK website[4]) • Useful cookbooks/ recipes (e.g. Coeliac UK website[4]) Formulate nutritional diagnosis and agree outcome measures (as per Trust guidelines). Record clearly any of above points not covered in initial review so can be discussed at review. Complete relevant letters to referrer and/or GP to include request for prescription of gluten free products, if appropriate. Advise patient initially to try a small amount but increase to monthly prescriptions when samples/products tried (monthly prescriptions are more cost effective). Prescriptions may be organised at first or second appointment depending on local policy. Add patient to coeliac database (if available – follow local Trust policy for medical/dietetic follow up).	DNA/two consecutive CNA's Patient does not consent to treatment Patient declines further input Patient not ready to commit to treatment programme
1st review at 6 - 12 weeks	**Assessment:** • Evaluate treatment goals and review achievement of nutrition outcomes set at initial assessment.	

30 - 45 minutes	• Biochemistry if repeated since last review e.g. coeliac serology, Hb, ferritin, folate, B12, thyroid function test • Weight (kg) and BMI • On-going symptoms - consider adherence, inadvertent ingestion of gluten or whether a need to follow “super sensitive method” eg avoidance of GF oats (reaction to avenin), any form of barley malt extract, Codex wheat starch) • Diet history, if appropriate • Understanding and adherence to gluten-free diet • Understanding of food labelling • Fibre intake • Calcium and lifestyle issues that can affect bone health (weight bearing activity, smoking, excess alcohol), assess need for supplementation – ensure calcium and vitamin D supplement used if needed (osteopenia/osteoporosis on bone scan) • Vitamin D – assess need for supplementation • Iron – assess need for supplementation • Access to prescribable products • Coeliac UK joined[d]/monthly updates • Achieving/maintaining healthy weight • GP/referral letter update if required – e.g. need for micronutrient supplementation, amendments to gluten-free product prescription • Further written information provided – Examples of information: • Osteoporosis/ calcium • Fibre • Holidays e.g. Coeliac UK website/dietarycard.co.uk • Baggage allowance letter • List of available cookery books	DNA/two consecutive CNA’s Patient does not consent to treatment Patient declines further input Patient not ready to commit to treatment programme/non compliance Treatment completed

2nd review at 3 – 6 months 30 - 45 minutes	As per first review. Nutritional intake and inadvertent intake of gluten can be assessed through diet history or from food diaries sent out prior to clinic/ domiciliary visit. Consider overall nutritional status/micronutrient requirements[e], inclusive of calcium, iron, fibre etc. Update on any new literature. Address any other issues e.g. weight gain[f] . If on-going symptoms and adherence verified, through dietary assessment or coeliac serology[g], refer back to the consultant for consideration of other problems e.g. coexistent IBD, microscopic colitis, small bowel bacterial overgrowth, lactose intolerance, pancreatic insufficiency, colon cancer, lymphoma, functional bowel disorders or very rarely refractory coeliac disease. GP/referrer letter update if required – e.g. need for micronutrient supplementation, amendments to gluten-free product prescription, on-going symptoms, review plans. Group sessions- if locally appropriate/ patient able to attend. Seek consent for patient discharge to group session.	As above
Annual review[f] (via one to one or group sessions) 45 minutes	Continue individual review appointments if necessary - e.g. on-going micronutrient deficiencies or patient preference. **Group sessions** - if locally appropriate/ patient able to attend. Or Discharge to Dietetic Led Coeliac Clinic if appropriate.	As above

References[1]

1. [1] National Institute for Health and Care Excellence (NICE, 2015) Coeliac disease: recognition, assessment and management. http://www.nice.org.uk/guidance/ng20.
2. NICE (2016) Quality Standard: coeliac disease https://www.nice.org.uk/guidance/qs134
3. BSG (2014) British Society of Gastroenterology. Diagnosis and management of adult coeliac disease: guidelines from the British Society of Gastroenterology. Gut 2014; 63: 1210-1228. Gut Online First, published on June 10, 2014 as 10.1136/gutjnl-2013-306578.
4. www.coeliac.org.uk

Additional notes:

a: It is essential that the patient has not removed gluten from their diet prior to their duodenal biopsy, and if they have it should be re-introduced for six weeks prior to testing. When following a gluten containing diet they should eat some gluten in more than one meal every day for 6 weeks before testing[1].

b: HLA typing can be used to rule out coeliac disease and minimise future testing, in high-risk individuals with CD, for example first degree relatives. However, a positive DQ2.5 or DQ8 can never confirm diagnosis. HLA typing may also be used in individuals who are self-treated on a gluten-free diet and never had appropriate testing before changing their diet [2].

c: Patients may commence gluten-free oats at diagnosis[2]. Originally oats were avoided in the gluten-free diet however research indicates that oats uncontaminated by gluten are probably safe for the majority of patients with coeliac disease. [2]. It must be emphasised to patients that oats used must be uncontaminated from gluten (check label or FDD to determine suitable brands).

d: It is estimated that 50% of patients with coeliac disease let their Coeliac UK membership lapse over time. All patients with coeliac disease should be encouraged and advised regarding the benefits of membership to Coeliac UK, the national support charity, at each review appointment.

e: Current figures estimate that 55% of those with coeliac disease are currently overweight or obese with only 38% being classified as having a normal weight for height ratio. It is quite likely that the trend for patients' increasing weight over time will continue and the advice given to patients in the dietetic clinic setting needs to reflect this.

f: Repeat coeliac serology (tTGA and EMA) is not routinely done for all patients in all Trusts as it is not a good marker to determine bowel recovery and those with negative serology may still have a degree of villous atrophy [2]. It can however be of benefit when appropriately used e.g. if a patient has ongoing symptoms and reports strict adherence to the gluten-free diet it can be used to rule out any inadvertent gluten ingestion.

g: Evidence supports the view that regular follow-up of people with coeliac disease/ dermatitis herpetiformis, ideally annually, improves the understanding of the condition, the adherence to the gluten-free diet, ensures monitoring of nutritional status and the assessment of short and long term complications[1,2] .

Of note: Dietetic Led Coeliac Clinics are ongoing in some Trusts, led by Advanced Practice Dietitians. This care pathway will be appropriate to follow, however additional responsibilities are required and in summary cover: pneumococcal vaccination advice, DEXA bone scan ordering and interpretation of results, relevant blood ordering and interpretation of results, symptom assessment and treatment with onward referral if required.