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PAEDIATRIC COELIAC DISEASE AND THE GLUTEN-FREE DIET

Coeliac disease (CD) is a systemic autoimmune disease which is caused by the immune system attacking healthy tissue due to the consumption of gluten.¹ The villi which line the small intestine are damaged and flattened causing the typical gastrointestinal symptoms.

Symptoms include: diarrhoea, constipation, wind, bloating, nausea, tiredness, weight loss or faltering growth, anaemia and hair loss. As these symptoms are quite general, CD can often go undiagnosed. CD is not always symptomatic and can also manifest itself as dermatitis herpetiformis, which is a skin condition also treated by a gluten-free diet.¹

According to Coeliac UK,¹ one in 100 people in the UK have CD; however, an estimated 24% of people are undiagnosed which is equivalent to nearly half a million people in the UK.¹ According to serological studies, 1% of children (up to 18 years of age) have CD.³ Socially deprived children have a lower chance of being diagnosed. In children aged two and over, CD has tripled over the last 20 years.²

CD is not an allergy or an intolerance. It is more prevalent in children who have other autoimmune diseases such as Type 1 diabetes and autoimmune thyroid disease. Certain variants of the HLA-DQA1 and HLA-DQB1 genes lead

to an increased risk of developing the disease. It tends to cluster in families; however, the inheritance pattern is unknown.⁴

SCREENING

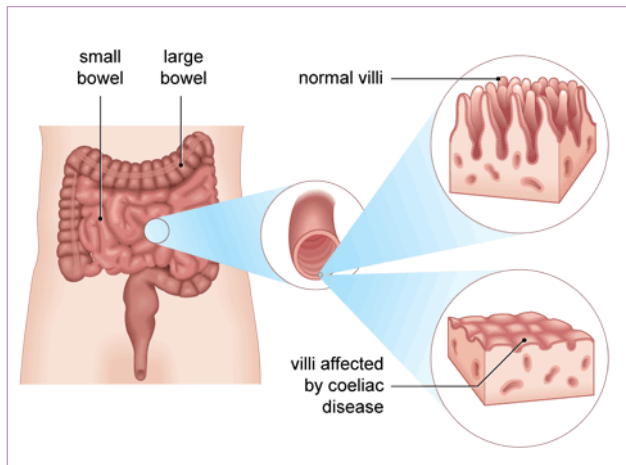
According to the NICE guideline on coeliac disease, serological testing should be offered to children with any of the following signs and symptoms:^{5,6}

- Persistent unexplained abdominal or gastrointestinal symptoms
- Faltering growth
- Prolonged fatigue
- Unexpected weight loss
- Severe or persistent mouth ulcers
- Unexplained iron, vitamin B12 or folate deficiency
- Type 1 diabetes, at diagnosis
- Autoimmune thyroid disease, at diagnosis
- First-degree relatives of people with CD

If children have any of the following, NICE also recommends that they have serological screening:⁵



Figure 1: The areas of the bowel affected by coeliac disease²



older children aim for 10-15g which equates to two larger portions of gluten containing foods; three meals would be preferable.⁷ It is possible to purchase gluten powder for parents who are struggling to increase their children's intake sufficiently through a normal diet. This can be added to other foods such as yoghurts or porridge and is available online and in some health food shops.

TREATMENT AND ROLE OF THE DIETITIAN

BSPGHAN and Coeliac UK recommend dietetic input at diagnosis, then three months after diagnosis, again at six months and annually after that.

The treatment for CD is a lifelong gluten-free diet. Dietitians are vital in providing education and support to families on diagnosis and beyond. If a gluten-free diet is not followed, it can lead to nutritional deficiencies such as anaemia and osteoporosis as well as cancer of the small bowel and infertility.⁸

At the initial dietetic assessment it is important to assess growth and start to plot on a growth chart⁷ in order to monitor in future reviews. Education is essential and it is always useful to check that patients and their families understand the condition before going ahead with providing advice. The diagnosis can be a lot to take in and often, in my experience, patients need a recap on what CD is and especially what it is not (an allergy or wheat intolerance) before proceeding.

It is best to do two diet histories. One for pre-coeliac disease to find out food preferences; in order to make patient-centred suggestions; and a history of the patient's current diet to establish if they are already following a gluten-free diet. This also gives you an opportunity to assess their knowledge.

- Metabolic bone disorder (reduced bone mineral density or osteomalacia)
- Unexplained neurological symptoms (particularly peripheral neuropathy or ataxia)
- Persistently raised liver enzymes with unknown cause
- Dental enamel defects
- Down's syndrome
- Turner syndrome

DIAGNOSIS

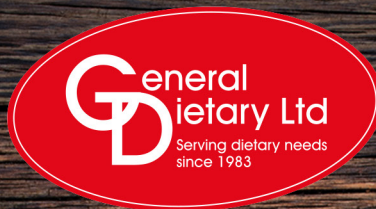
As mentioned above, a huge amount of children and young people have CD and are not diagnosed. See Figures 2 and 3 for details regarding diagnosis and when a duodenal biopsy is required.

To avoid a false negative result, people need to continue consuming gluten daily for at least six weeks before any testing.⁶ This can be very difficult, especially with children, as it is difficult to explain, causes discomfort and can be distressing for parents and carers.

The advice is to aim for 10g of gluten per day for infants and young children. Two meals per day containing at least 5g of gluten, such as wheat cereal, pasta or bread, should be sufficient. For all



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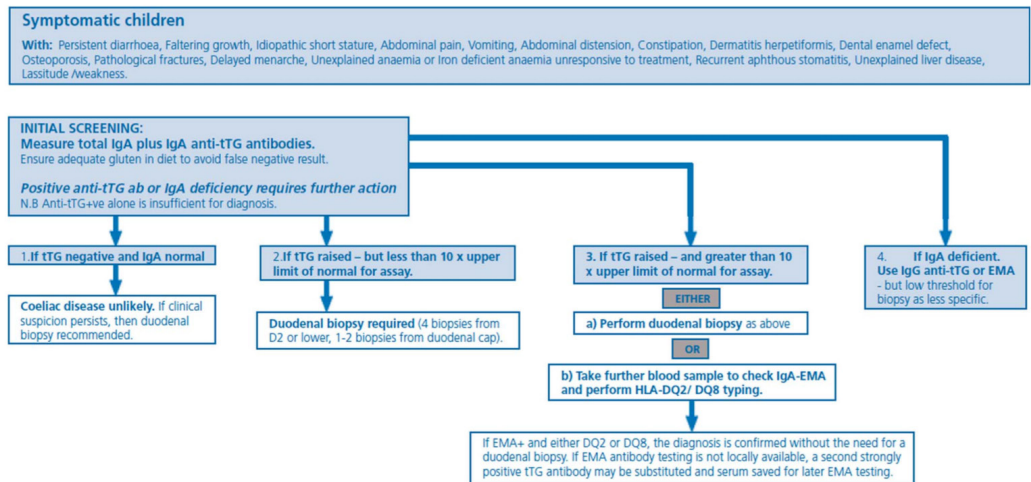
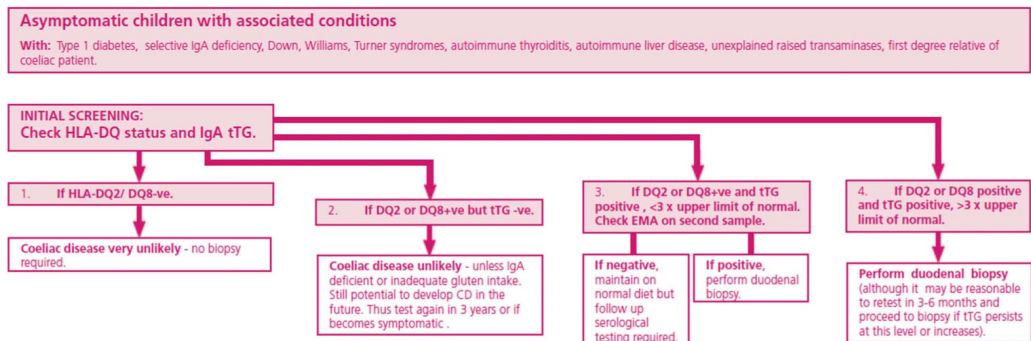
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Figure 2: Outline stratagem for symptomatic children⁷Figure 3: Outline stratagem for asymptomatic children with associated conditions⁷

Education should include the following topics:

- What grains contain gluten
- How to follow a gluten-free diet
- Reading labels
- EU legislation regarding food labelling and cross contamination

Eating out can often prove to be difficult; however, legislation now states that caterers have to provide allergen information. This does not mean that they have to cater for people with CD. It is always best to contact caterers in advance to give them notice to provide a gluten-free meal. It may be necessary to educate the caterer on gluten-free food and cross contamination.

Oats are a contentious issue, as often parents want to use them as a substitute, ideally they

should be avoided for a year, or until the child has reverted to the healthy state they were in before diagnosis.⁷

Lactose intolerance can sometimes occur if a patient's gut has been damaged in the location that lactase is produced. This is usually temporary and will resolve a few weeks after a gluten-free diet is commenced.

The charity Coeliac UK have local support groups which can be very useful for families trying to cope with the diagnosis. Often better practical advice comes from other families who have been through the same thing. It is good practice for dietitians to experience a gluten-free diet for themselves and to perhaps trial it for a week; it is easier to empathise with people when you have experienced it yourself.

Table 1: Reference Nutrient Intakes

CALCIUM		IRON	
0-1	525mg/day	0-3 months	1.7mg/day
1-3	350mg/day	4-6 months	4.3mg/day
4-6 years	450mg/day	7-12 months	7.8mg/day
7-10 years	550mg/day	1-3 years	6.9mg/day
Males		4-6 years	6.1mg/day
11-18 years	1000mg/day	7-10 years	8.7mg/day
Females		Males	
11-18 years	800mg/day	11-18 years	11.3mg/day
		19 years +	8.7mg/day
		Females	
		11-50 years	14.8mg/day
		50 years +	8.7mg/day

In the first appointment with a newly diagnosed Coeliac, it is normal to discuss prescription items and what people are entitled to. The Coeliac UK website has a Prescribable Products List.⁹

Gluten-free foods with ACBS approval⁹

- Bread / rolls
- Breakfast cereals
- Crackers and crispbreads
- Flour / flour-type mixes
- Oats
- Pasta
- Pizza bases

However, over a third of Clinical Commissioning Groups (CCGs) are now restricting GPs prescribing gluten-free items due to demands to save money. Check out CCGs on the Coeliac UK website,¹⁰ they have a pretty nifty interactive gluten-free prescribing map of England.

It is important to look out for signs of anxiety or depression in children and parents and carers. Living with CD can be a burden, as with any other long-term health condition.⁶ If you are concerned about mental health problems, ensure that you communicate with the multidisciplinary team and the primary health team, such as a GP, health visitor or school nurse.

REVIEW

After three months, the dietitian should review growth and assess the diet again for adherence to a gluten-free diet. Usually, patients will start to feel better after a few weeks and at this review the patient will hopefully be doing just that. If children are still experiencing symptoms, a

detailed diet history will be needed to explore potential contamination of gluten. If after a further three months symptoms continue, further investigations will be needed to explore whether the child has any other allergies or intolerances.

Motivation to follow a gluten-free diet may wane and it is important to encourage patients and their carers to continue. It can be more difficult when children are asymptomatic, as they do not associate eating gluten with the disease.

At the three-month review, it is important to review dietary intake of iron and calcium. Coeliac children do not need extra calcium or iron compared to other children; nevertheless, it is important that they are meeting their Reference Nutrient Intakes (RNIs). See table 1.¹¹

Also ensure that children are getting enough vitamin D. Parents should be giving 0-1 year olds 8.5-10ug per day and everybody else (including adults) 10ug per day all year round.¹³ It is now thought that UK residents are unlikely to get enough vitamin D from UVB radiation from September through to April.¹²

CONCLUSION

Coeliac disease is a lifelong condition; all of the symptoms and risks to health can be reversed by following a gluten-free diet. It is vital that we as healthcare professionals support families to adhere to the gluten-free diet and promote healthy eating within it to optimise the health and development of children with CD.

Questions relating to: *Paediatric coeliac disease and the gluten-free diet.*

Type your answers below, download and save or print for your records, or print and complete by hand.

Q.1 Describe the aetiology of coeliac disease (CD).

A

Q.2 Explain the prevalence of CD in the UK.

A

Q.3 When should serological testing in children take place?

A

Q.4 What is the dietary advice to avoid a false negative result in testing of CD?

A

Q.5 Outline the stratagem for symptomatic children if tTG is raised.

A

Q.6 Explain the treatment for CD and risk if treatment is not consistent.

A

Q.7 Describe the in dietetic assessment and management of CD patients.

A

Q.8 Describe the dietetic assessment and management of CD patients.

A

Please type additional notes here . . .