



So Many Patients Too Little Time A Dietetic Led Service

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“Classical” Case

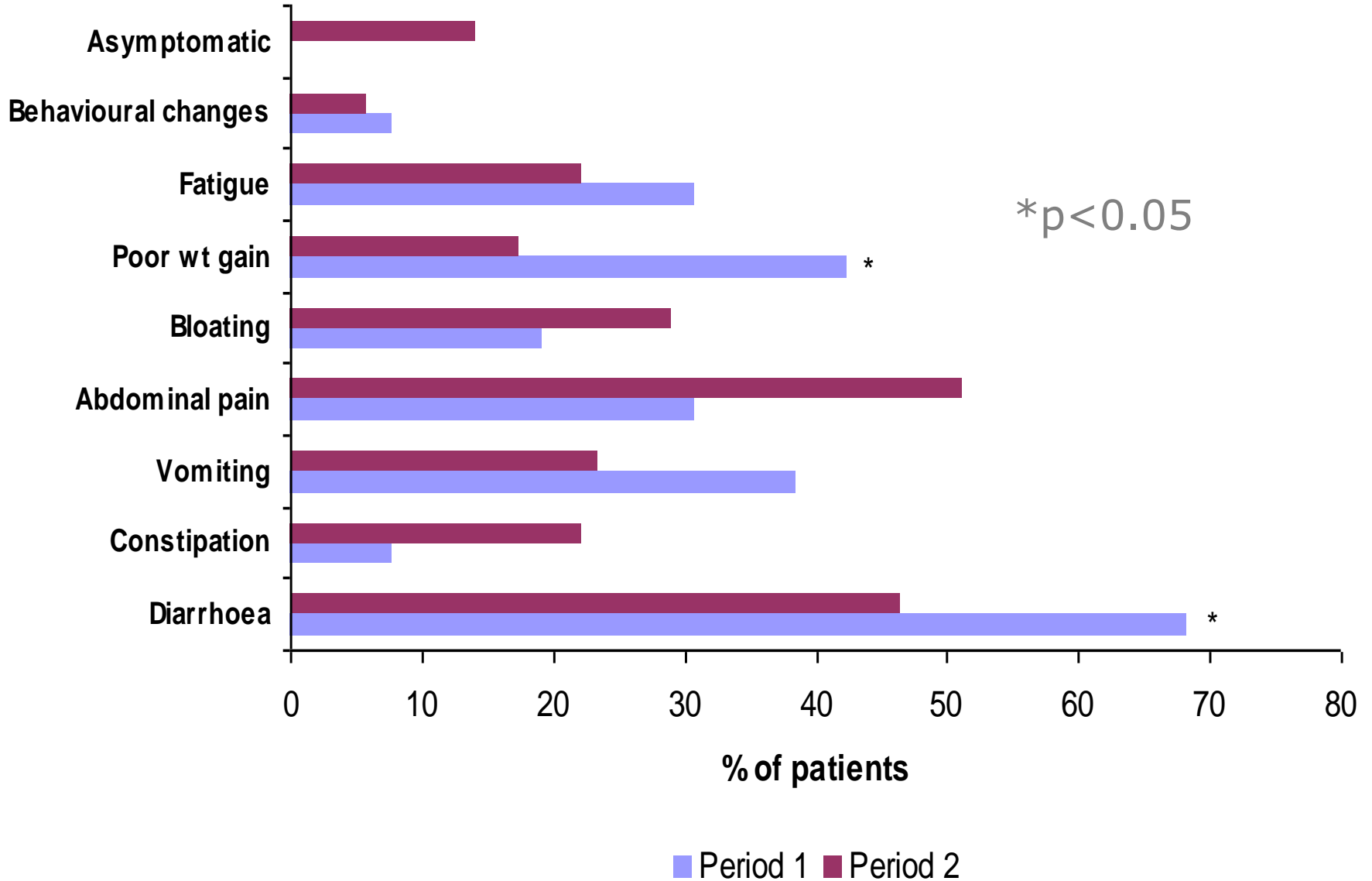
- Diarrhoea
- Faltering growth
- Vomiting
- Anorexia and weight loss
- Short stature
- Protuberant abdomen
- Irritability



More Subtle Presentations

- Tiredness
- Frequent infections
- Constipation / rectal prolapse
- Pallor / anaemia
- Mouth ulcers, dental enamel defects
- IBS type symptoms

Clinical presentation of children with CD in two different periods



New Guidelines (2012)

ESPGHAN¹/BSPGHAN²



Serology used for diagnosis

- Symptomatic pt
- Asymptomatic pt with associated condition

1. Husby S et al (2012). ESPGHAN Guidelines for the diagnosis of coeliac disease in children and adolescents. An evidence-based approach. *JPGN*. 54; 136-160

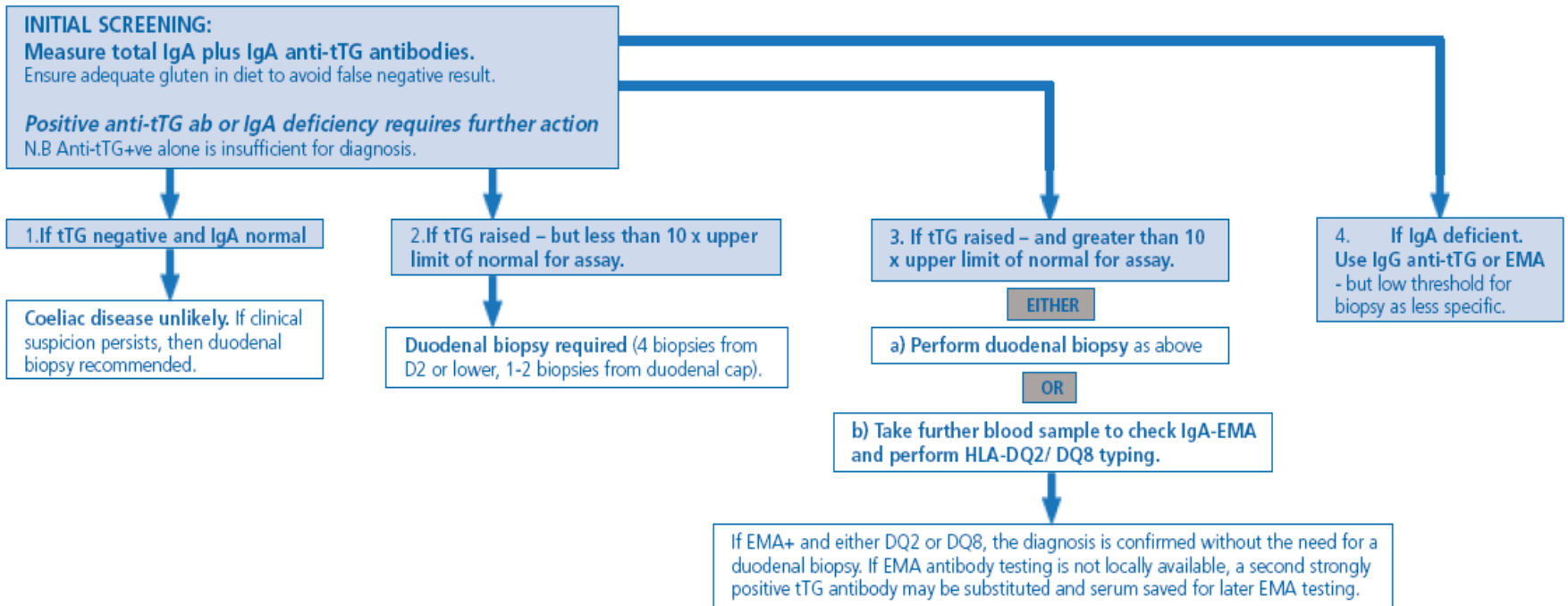
2. Coeliac Working Group of BSPGHAN (2012). Guideline for the diagnosis and management of coeliac disease in children. www.coeliac.org.uk

Guideline for the diagnosis and management of coeliac disease in children

Who to test

Symptomatic children

With: Persistent diarrhoea, Faltering growth, Idiopathic short stature, Abdominal pain, Vomiting, Abdominal distension, Constipation, Dermatitis herpetiformis, Dental enamel defect, Osteoporosis, Pathological fractures, Delayed menarche, Unexplained anaemia or Iron deficient anaemia unresponsive to treatment, Recurrent aphthous stomatitis, Unexplained liver disease, Lassitude /weakness.

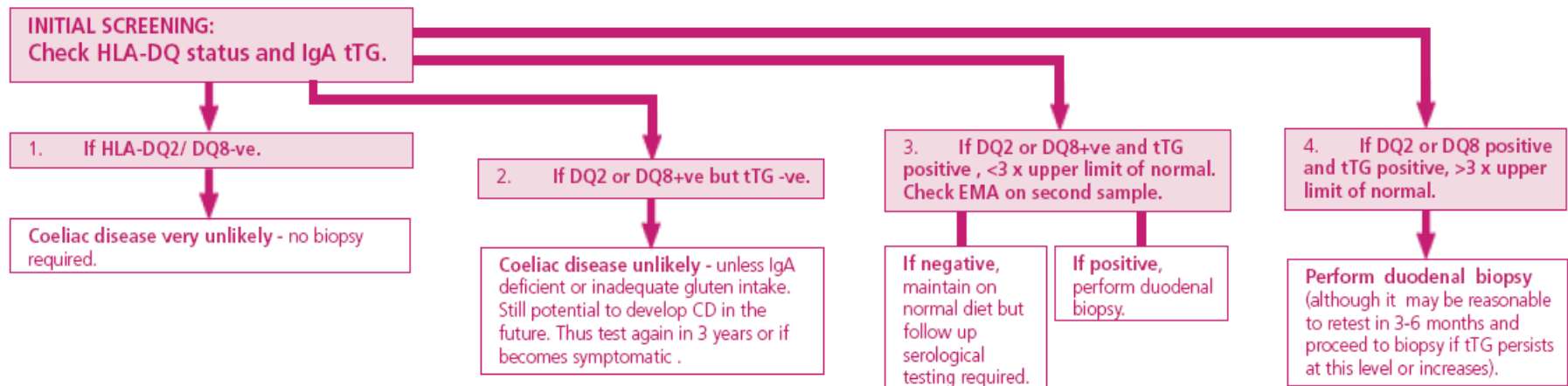


Guideline for the diagnosis and management of coeliac disease in children

Who to test

Asymptomatic children with associated conditions

With: Type 1 diabetes, selective IgA deficiency, Down, Williams, Turner syndromes, autoimmune thyroiditis, autoimmune liver disease, unexplained raised transaminases, first degree relative of coeliac patient.

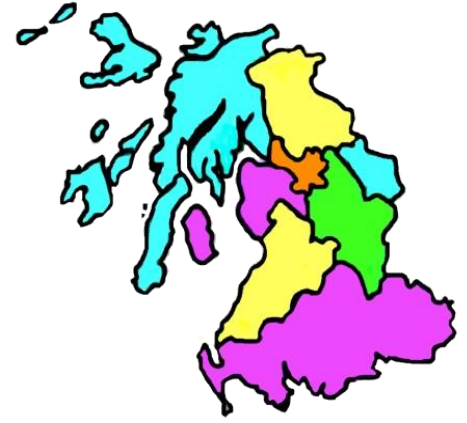


Benefits

- Not all children require a biopsy
- More timely diagnosis
- Cost savings
 - » Gastroenterology
 - » Anaesthetics
 - » Day surgery
 - » Pathology

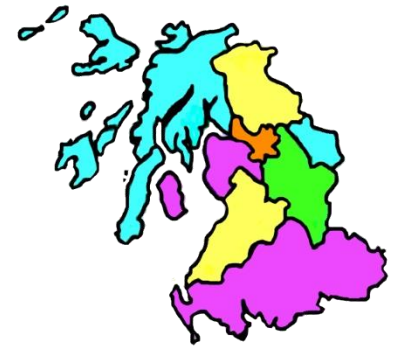


Background



- Uncoordinated service
- No protocols/pathways
- Basic database
- Inadequate dietetic support

Background



- Patients seen by 4 Consultant Gastroenterologists
- 1.0 WTE Gastroenterology Dietitian
- 4 GI clinics with wide variety of clinical conditions

Background



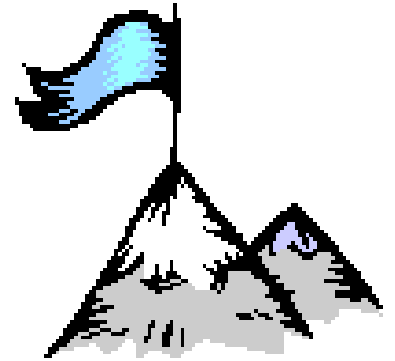
- No consistent approach between medical staff
- New coeliac patients seen out with clinics
- No clinic cover if dietitian on leave
- Patient questionnaire re coeliac clinic

Proposal



- Dietitians manage all patients with coeliac disease from initial referral through diagnosis and follow up to transfer
- Complex patients with coeliac disease will attend GI clinic
- Additional funding for extra dietetic hours and clerical support → business plan
- Designated clinic once fortnightly
- Education at clinics
- Comprehensive database

Initial Challenges



- Funding
- Dedicated clinic space
- Paper work associated with setting up a clinic
- Agreement from Biochemistry and Haematology to allow dietitian to order bloods
- Agreement with Out Patient clinic staff to measure height, weight and taking blood
- Agreement of all GI Consultants
- Ensuring pathway and documentation is clear
- Accessibility of medical staff if there is a clinical problem

Initial Service Development

- Business plan→ additional 1wte dietitian
- Competency framework for advanced role
- Protocols and pathways
- Database development

Dietetic Led Service

- Patient/Carer Consultation
- Clinic established in Glasgow in 2007
- Pathways and protocols established
- Advanced role for dietitians

Competency

- Extended role
- Education and training
- Competency framework
- Annual assessment
- Regular MDT meetings with Lead Clinician

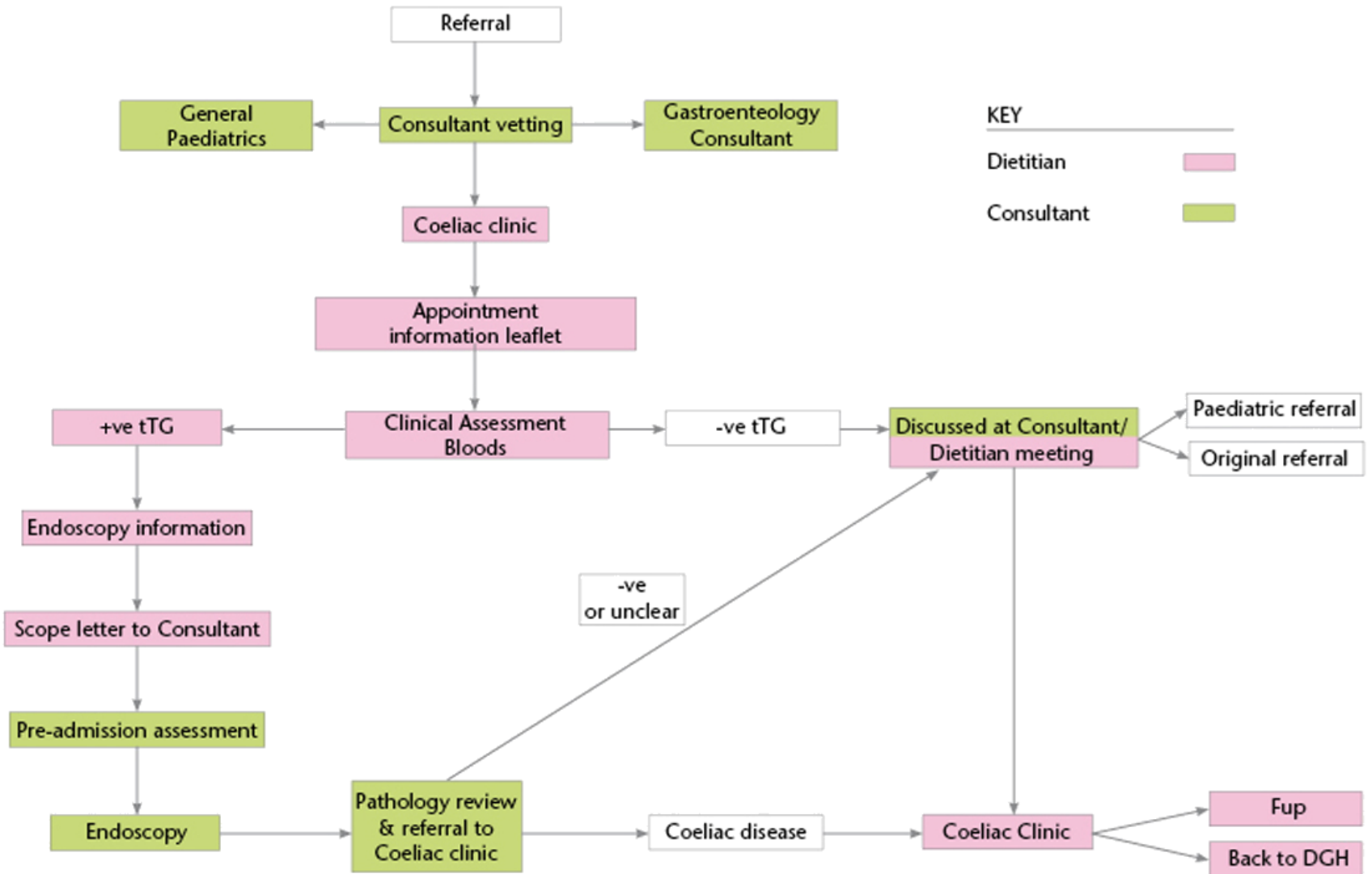


Referral Criteria

- Positive coeliac serology± symptoms
- Strong family history + positive coeliac serology
- Type 1 DM + positive coeliac serology
- Dermatitis Herpetiformis





Dietetic Led Coeliac Clinic



Literature Development

NHS
Greater Glasgow
and Clyde

Women and Children's Directorate






Dietetic Led Coeliac Clinic

Referrals
Patient Information

NHS
Greater Glasgow
and Clyde

Women and Children's Directorate





Dietetic Led Coeliac Clinic

General Information

NHS
Greater Glasgow
and Clyde

Women and Children's Directorate



Upper G.I Endoscopy

Teenager Information Leaflet

NHS
Greater Glasgow
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Women & Children's Directorate


Screening for Coeliac Disease in Families

Coeliac disease is a lifelong condition and is an intolerance to gluten. Gluten is the protein which is found in wheat, rye, barley and oats.

Coeliac disease does tend to run in families. Recent research has found that there is a genetic link to coeliac disease. One in ten relatives of a person diagnosed with coeliac disease may also be affected.

We would therefore recommend that all the family are tested by your GP to find out if they may have coeliac disease. This involves a simple blood test and you should discuss this with your GP. It is especially important if any of the other family members develop symptoms.

Coeliac disease is also more common if you have certain other medical conditions. These include diabetes, thyroid problems and immune problems



NHS
Greater Glasgow
and Clyde

Women & Children's Directorate

HLA Typing in coeliac disease

There are specific blood tests used in the diagnosis of coeliac disease. They look for antibodies that the body makes in response to eating gluten. One of these is called a tTG (Tissue Transglutaminase) antibody and you may have had a level that is higher than it should be. This shows that you may have coeliac disease, but your biopsy does not clearly suggest that you have this condition.

In cases like this, we can offer you a blood test which may help us find out if you have the same risk of developing coeliac disease as the general population, or if you are very unlikely to develop the condition. This test is called HLA typing.

What is HLA typing?

HLA stands for Human Leukocyte Antigen and is related to our immune system. It looks for genetic markers in our blood.


A negative HLA result shows that you are not likely to develop coeliac disease and you will not need any more tests for this.

A positive HLA result will mean that further review is necessary, as you may still possibly develop coeliac disease at some point in the future.

A repeat biopsy may be necessary depending on how well you remain.

The HLA typing helps us consider the risk of coeliac disease and does not look at any other conditions.

If you have any further questions, please contact the Gastroenterology Dietitians on the number: 0141 201 0846



Medical Illustration Services • Tel: 0141 211 4892 • E-mail: medical@nhs.uk • NHS 24/7

Women and Children's Directorate

Coeliac Clinic - New patient referral

Please attach patient label here

Clinic Date.....

Presenting Symptoms

Family History

Allergies

Previous General Anaesthetic Y/N

Any Difficulties Y/N

Other physical problems

Height..... Centile..... Growth: Satisfactory/Unsatisfactory
Weight..... Centile..... Parental Height Mother.....
Father.....

Dietary Assessment

Gluten intake Adequate/Inadequate

	Bloods taken Y/N	Result Normal/Abnormal
tTG antibodies		
Full blood count		
LFT's		
U+E's		
TFT		
PTH		
25HCC (vitamin D)		
Ferritin		
Folate		
Coagulation		

Medications

Other relevant information

Endoscopy Information Given Y/N

Follow up

Signature..... Date.....

Symptoms			Comment
Appetite	Normal	Abnormal	
Energy	Normal	Abnormal	
Abdo pain	none	mild moderate severe	
		Non specific epigastric central lower	
		Associated with defaecation	Y N
		Nocturnal waking	Y N
Stooling	Freq/day		
		Loose soft normal hard	
		Flush away	Y N
		Blood	Y N %
		Perianal pain	Y N
		Nocturnal defaecation	Y N
Rectal Prolapse	Y	N	
Abdo distension	Y	N	
Vomiting	Y	N	
- Bilious	Y	N	
- Blood	Y	N	
Mouth Ulcers	Y	N	
Dental problems	Y	N	
Skin Problems	Y	N	
Bruising	Normal	Abnormal	
Nose Bleeds	N	Infrequent	Frequent
Menarche	Y	N	
Periods	Regular	Irregular	
Other			
Dietitian.....	Date.....		

Coeliac Clinic

- New Referrals and diagnoses
- Review at 3 & 6 months & annually
- Clinical assessment
- Blood monitoring
- Patients seen more frequently if concerns
- Pubertal status self assessment >10years



Securing a Diagnosis

- Ensure adequate gluten
- IgA tTG's/ EMA or IgG tTG/EMA
- HLA typing
- Option of biopsy in all cases and all patients < 2years require a biopsy



Diagnosis

- Serology with positive HLA typing
- Biopsy
- All diagnosis confirmed in writing

Initiation of Gluten Free Diet

- Within 1-2 weeks of diagnosis
- See patient and relevant family members
- Arrange interpreter if required
- 1 hour appointment slot



Coeliac Pack

- A Guide to gluten free living
- Starter pack cards from companies
- Prescribable items
- Coeliac UK information
- Clinic information
- Family screening
- Contact details

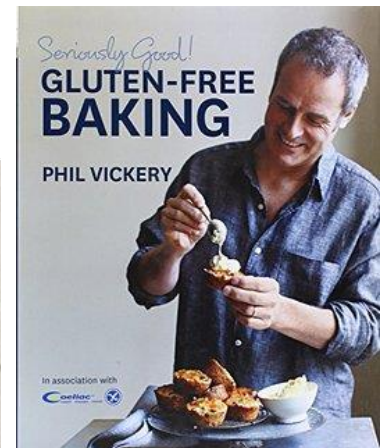




Information



Coeliac Awareness Week - 13-20 March



Follow Up

- Telephone clinic appointment in 2 weeks
- Generic email contact
- Clinic review 3m, 6m, and annually
- Letters to families re bloods
- Review more frequently if concerns

Follow Up

- Height and Weight
- Review symptoms
- Assess compliance - Patient/Carer
- Professional
- Bloods at 6m and annually
- ? Coeliac UK members
- ? Prescription Items
- ? School/nursery

Transition

- Start discussing from 14 years
- See patients on their own
- Encourage independence
- Transfer to adult services 16 years



Transition

- Different model in adults
- Referred to Gastroenterologist & Dietitian
- Dietetic review until age 19 yrs
- Annual review by Pharmacy



Patients Yorkhill Status: Active - RHSC

Details of Yorkhill Discharge Other:

Patients DGH Status:

Details of DGH Discharge:

Diagnosis: Coeliac

Date of Diagnosis: 09/02/2015

Discharge/ Transfer RHSC Date:

Discharge DGH Date:

Save record and return to main switchboard

Pathology Record

Height and Weight

Blood Records

tTG Antibodies	FBC	LFT	Us and Es	TFT	PTH	25HCC (vit D)	Ferratin	Folate	IgA	IgGEMA	IgEMA
17		Normal		Normal	0	0	0				
27					0	0	0				
>128	Abnormal	Normal	Normal	Normal	0	68	4		Normal		
					0	0	0				

A review of changes in presentation of Coeliac Disease within our centre and comparison with 2009 data set



H Duncan¹, E Buchanan¹, T Cardigan¹, RK Russell²
1. Department of Nutrition & Dietetics 2. Paediatric Gastroenterology Department

Length of time for tTG antibody levels to normalise following diagnosis of Coeliac Disease in a paediatric cohort



E Buchanan, H Duncan, T Cardigan¹, RK Russell²
1. Department of Nutrition & Dietetics 2. Paediatric Gastroenterology Department

Education



Education

- Family and Professional Education Days
- Development of videos for patient access



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Paediatric Coeliac Disease

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NHSGGC - Coeliac UK
 by nhsggc 1:10

A DIETETIC LED COELIAC SERVICE: PATIENT AND CLINICIAN SATISFACTION

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Figure 2: Satisfaction of the Dietetic Led Coeliac Service for Parents/
Carers

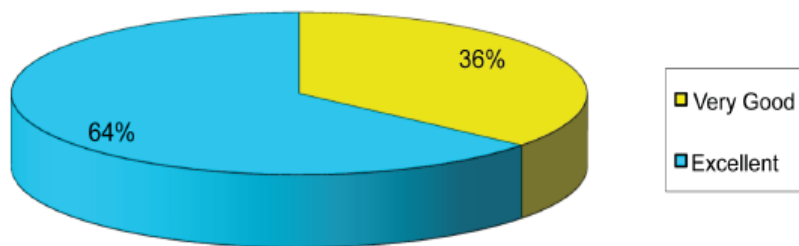
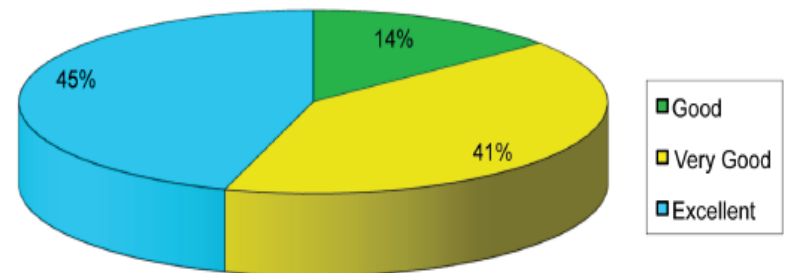


Figure 3: Satisfaction of the Dietetic Led Coeliac Service for Clinicians



Current Service

- Over 275 patients
- 1 - 2 new referrals weekly
- 2 clinics weekly
- 3 new patient appointments and 9 follow up appointments

Coeliac Service

- Identified parents and siblings with CD
- 3 patients with autoimmune hepatitis
- Abnormal thyroid function tests
- 4 patients with Crohn's disease

In Summary

- Advanced role for dietitians
- Improved patient care
- Improved equity of care across the West of Scotland
- Professional autonomy
- Unique service

coeliacuk
live well **gluten free**

