Symposium 1
Living with Coeliac Disease
What about oats?

- Emile Richman
  Gastroenterology Dietitian
The Plan..

- The history of oats in coeliac disease.
- Review the reviews.
- The latest study in GUT.
- The ups and downs of oats.
- Handling the risk.
This talk is not a zebra.
More like a Goat…
History

• 1888 First described by Dr Sammuel Gee. Children improved enormously on a diet of Dutch mussels, but relapsed when the Mussel season was over!

• 1950 Dicke identified wheat and Rye harmful to people with coeliac disease

• 1953 Van de Kamer suggested oats a problem.
1953 - 2007

- Two systematic reviews:
- 21 clinical studies on oats and coeliac disease. “Add oats when established on gluten free diet and stop if develop symptoms”.
“Patients with coeliac disease wishing to consume diet containing oats should therefore receive regular follow-up, including small bowel biopsy at a specialist clinic for life”.
How often Biopsy?

(BSG Guidelines on Coeliac disease 2010)
Taxonomy of OATS

Cereal grains are taxonomically classified in the Poaceae family (which has several subfamilies).

The Festucoidae subfamily contains the cereals wheat, barley, oats and rye.
Proteins in Barley, Wheat, Oats and Rye
Recent study in Gut.

- Three groups of oat cultivars reacting differently against the monoclonal Antibody G12 could be distinguished:
  - A group with considerable affinity.
  - A group showing slight reactivity.
  - A third group with no detectable reactivity.
Dilemmas

• 1. Antibody efficacy - Normalisation of coeliac antibodies does NOT guarantee villus atrophy improved (Kaukinen K, 2007).

• 2. 34% patients with raised TTG antibody levels at 12 months had NORMAL HISTOLOGY (Shepherd S 2008).

• 3. Symptom assessment is not a reliable method of assessing bowel villous atrophy (Haines, 2008).
Upside of oats

• Increased access to nutrients.
• Beta glucan and cholesterol.
• Low glycaemic index.
• NICE guidelines I.B.S. 2010
• Increase fibre decreases risk of colorectal cancer (BMJ 11.11.11).
Peer conformity decreasing anxiety? (Bridcut E Gut 2008)
Downside

• Cost of clean oats.

• Decreased stature following hunter gather move to agrarian dwellers.

(Ludwig 2011 J.A.M.A.)
Gluten free diet circa 20,000 B.C.
(Fasano A. New England Journal of Medicine 2003)
In practice

- Different hospitals have different hospital policies.
  
  Telephone survey to hospital dietetic departments (n=4)
  “What is your policy on oats and coeliac disease?”

1. No oats at all (paediatric hospital).
2. Introduce oats at 6 months if symptom free.
3. Introduce oats at 12 months if symptom free.
3. Introduce oats at 6 months if symptom free and then get repeat T.T.G.
Risk

• Are humans good at calculating risks?
Not according to Tversky?
(Nobel Prize 2002)
National Lottery

• When do you buy your ticket to be more likely to win than die if the chances are 14 million to 1 of winning?
What is health about?
The Limits to medicine
Can I eat oats if I have coeliac disease?
COPING WITH COELIAC DISEASE

A Patient’s Perspective

Carolyn May
BAPEN 2011

carolynalmay@hotmail.com
Agenda

• My own history
• Issues with diagnosis
• Social restrictions
• Work-related issues
• Anxiety & depression
• Ongoing medical issues
• Everyone is different
• Areas for research?
• A few quotes from coeliacs
My own history

- Originally chartered accountant but now work for Monitor in Strategy team
- Misdiagnosed for years when trying to compete for GB and then Oxford University in athletics
- “A virus”, “muscle fatigue”, “anorexia”, “too much stress”, “grumbling appendix”
- Only diagnosed eventually due to a parasite and a mother’s love
Issues with diagnosis

• IBS!!!!!!!!!!!!!!!!!!!!!!!
• Dermatitis Herpetiformis often not recognised as such
• People with thyroid problems should be tested for CD?
• Ditto unexplained anaemia, low B12?
• Ditto osteoporosis?
• Ditto unexplained infertility?
• Ditto ear infections in babies?
• Importance of testing family members for CD
• Undiagnosed coeliacs may be overweight, not underweight
• Incorrect medical advice pre diagnosis. i.e "try going gluten free and then we'll test you if you feel good on it" prolongs diagnosis and contributes towards false negatives
You’re a what???
Social restrictions

• Eating out in restaurants
• Eating at family and friends’ houses – lack of understanding – cross contamination etc
• Carrying food around
• Holiday restrictions – self-catering
• Impact on relationships – the other person has to suffer too! Puts a huge amount of strain on the coeliac
• Especially hard for children and adolescents
Work-related issues

- Not being able to take jobs involving working abroad / regular hotel stays
- Working lunches / dinners difficult – isolating
- Unsafe / inadequate food provided, even exclusion
- Fear of job loss through time off sick
Anxiety

- Constantly thinking about and planning your next meal
- Constant examination of food and drink ingredients and difficulty in trusting
- What is the damage when mistakes occur?
- Lack of safe food in hospitals!
- How will others react? Potential partners, friends, work colleagues
- Cost (prescriptions debate)
Depression

- At the life-long nature of the condition and restrictions
- At the prospect of other complications
- At the difficulty placed on close relationships and prospect of being alone
- Having to be “different” and also watch others enjoy things you are no longer allowed – feels like being punished
Ongoing medical issues

- Little awareness of connected conditions: osteoporosis, Type I diabetes, RA, autism, liver problems etc.
- Lactose intolerance often found with CD
- Pancreatic insufficiency, gallstones common – enzymes?
- SIBO common – antibiotics can massively help
- DEXA scans needed for diagnosed coeliacs
- General failure to heal – why if gluten is the only issue?
Difficulty that everyone is different

- Many cannot tolerate wheat-derived products which are gluten free, e.g. glucose-fructose syrup, dextrose – why?
- Some are more sensitive than others – why?
- Some find 20ppm still an issue
- Some have problems with casein, soya, corn, even rice
- Grain based alcohols affect some people – yes, could be alcohol per se or the yeast of course
A few other thoughts for research

• Some coeliacs seem to have an issue with other grains. Many report success on “Specific Carbohydrate Diet” (aims to rebalance gut flora and reduce bacterial overgrowth from poor digestion of polysaccharides) – is gluten the whole story?

• Others seem to have an issue with oats, corn, even rice. Is there a “typical coeliac” or just a spectrum? Genetic / mucosal screening possible for other food sensitivities?

• Many coeliacs report some triggering incident such as a parasite, virus or bacteria. Does this underlying incident still need treating? Is there an underlying bacterium / virus that has not been discovered?

• Many report improvement when on antibiotics – implies a bacterial overgrowth connection? Spanish researchers showing improvement with bifidobacteria probiotics? Probiotics the future? Faecal bacteriotherapy?

• Hepatitis B vaccine doesn’t work in coeliacs – is there a connection here? Could the vaccine itself trigger something?

• Is impaired motility the issue? Damage to the muscles / nerves in the gut in some way? Can they be repaired?

• Controversial! Mercury appears to block the DPP-IV enzyme that digests gluten and casein – is this worth exploring? i.e amalgam fillings, contaminated fish? Grains contaminated with heavy metals?
If you really want to know what it’s like..

http://members2.boardhost.com/glutenfree/
A few quotes from the gluten free message board

• Agree about IBS - I also was misdiagnosed for about 10 years with this. Wasn't tested for a single damn thing, was "diagnosed" with IBS on the basis of 5 minutes, which is appalling as IBS is a diagnosis of 'elimination' when everything else has been tested for.

• Not everyone has a family history, e.g. I was the first one in my family to get dx, and faced barriers because of that, now there are 4 of us that I know of. I also had a GP tell me I couldn't have CD, you have CD from birth so I'd know by now if I had it...erm, what?!

• Still some really outdated information out there in general practice. IBS should be bloody banned IMHO, very lazy label to use all over the place.
More quotes

• I guess my area for you to comment on would be the lack of knowledge by other doctors and how their knowledge needs to be increased because CD does affect other parts of the body etc. However, by the sounds of things those wouldn't be the ones attending!

• Lack of knowledge of CD among many dieticians. I saw two after diagnosis and knew more than them thanks to this board and internet searches. Indeed, thanks to those sources I think many coeliacs know more about their condition than the GPs they are seeing. Perhaps also the fact many coeliacs get Diagnosed, put on Diet and then Discharged, the three D's of dealing with them.
Thanks for listening.

Questions?
“We Are Diagnosing & Treating Too Many People with Coeliac Disease?”

Dr Neil Haslam
Consultant Endoscopist
Royal Liverpool University Hospital
Debate Health Warning

• Out to win debate
• Very little evidence
• No RCTs
• Lots of Anecdotes
• Lots of Emotion
• Some underhand tactics
• A lot like the X Factor
2 Davids?
A Cautionary Tale

Grandma Rogerson Age 85
Coeliac Disease in the 21st Century
The New Coeliac Patient

- Middle aged lady
- Presents with Iron Deficiency Anaemia
- Has a positive tTG Ab
- OGD and D2 biopsy confirms Coeliac disease
- Placed on Gluten free diet
- Dexa Scan booked
- Advise on immunisation given
- Clinic follow up in 1 year
1 Year Follow Up

• Not happy
• Don’t like diet
• Cannot drink beer or eat cakes and sandwiches
• Cheat, but feel guilty
• Put on weight
• Don’t feel any better
Undiagnosed Coeliac Disease: Is it a Disease?

- Gastroenterology 2010:139;763-769.
  “Morbidity and mortality among older individuals with undiagnosed Coeliac Disease”

With the exception of reduced bone mass limited co-morbidity and no excess mortality in undiagnosed Coeliacs

PLUS lower BMI and Cholesterol levels
Quality of Life in Coeliac Disease is Determined by Perceived Degree of Difficulty Adhering to a Gluten-Free Diet, not the Level of Dietary Adherence Ultimately Achieved

Stephen M. Barratt, John S. Leeds, David S. Sanders

The Gastroenterology & Liver Unit, The Royal Hallamshire Hospital, Sheffield Teaching Hospitals, NHS Foundation Trust, United Kingdom
Subliminal Advertising
Population Screening
World Health Organization — Principles of Screening

- World Health Organization guidelines were published in 1968, but are still applicable today.

- The condition should be an important health problem.
- There should be a treatment for the condition.
- Facilities for diagnosis and treatment should be available.
- There should be a latent stage of the disease.
- There should be a test or examination for the condition.
- The test should be acceptable to the population.
- The natural history of the disease should be adequately understood.
- There should be an agreed policy on whom to treat.
- The total cost of finding a case should be economically balanced in relation to medical expenditure as a whole.
- Case-finding should be a continuous process, not just a "once and for all" project.
Screening For Coeliac Disease

• WHO 1st Principle

• The condition should be an important health problem

• Undiagnosed Coeliac Disease is not an important health problem
If you ever think screening-
Think Betty’s
Who should be tested?

• NICE Guidelines May 2009.
NICE Guidelines

Signs and symptoms

- Chronic or intermittent diarrhoea
- Failure to thrive or faltering growth (in children)
- Persistent or unexplained gastrointestinal symptoms including nausea and vomiting
- Prolonged fatigue (‘tired all the time’)
- Recurrent abdominal pain,
- cramping or distension
- Sudden or unexpected weight loss
- Unexplained iron-deficiency anaemia, or other unspecified anaemia
NICE Conditions

Conditions

• Autoimmune thyroid disease
• Dermatitis herpetiformis
• Irritable bowel syndrome
• Type 1 diabetes
• First-degree relatives (parents, siblings or children) with coeliac disease
Consider Testing

• Addison’s disease
• Amenorrhoea
• Aphthous stomatitis (mouth ulcers)
• Autoimmune liver conditions
• Autoimmune myocarditis
• Chronic thrombocytopenia purpura
• Dental enamel defects
• Depression or bipolar disorder
• Down’s syndrome
• Epilepsy
• Low-trauma fracture
• Lymphoma
• Metabolic bone disease
Consider testing

- Microscopic colitis
- Persistent or unexplained constipation
- Persistently raised liver enzymes with unknown cause
- Polyneuropathy
- Recurrent miscarriage
- Reduced bone mineral density
- Sarcoidosis
- Sjögren’s syndrome
- Turner syndrome
- Unexplained alopecia
- Unexplained subfertility
Sounds Like Screening By Stealth?

• A straw poll of the audience
The Power Of GFD

• Bury 2000
• Diabetologist asked for D2 Biopsy
• “Brittle Diabetic”
• Coeliac Disease diagnosed
• GFD Started
• Diabetic control revolutionised
The Power Of GFD 2
GFD: A Life Sentence?
Time For A New Paradigm

- Diagnose Coeliac Disease
- Trial of GFD
- Review at 1 year
- Mature discussion on Pros and Cons
- Discontinue diet without guilt
Vote Time
Conclusion

• Undiagnosed Coeliac Disease is not a disease
• Screening should not happen
• Happy to diagnose Coeliac Disease
• BUT, we need a new adult attitude to treatment
• Trial a GFD
• Stop GFD without guilt
Thank You
We are diagnosing and treating too many people with coeliac disease?

Tuesday 29th November 2011

Professor David S Sanders
Consultant Gastroenterologist
Royal Hallamshire Hospital & University of Sheffield
Ouch! ok, ok you win Neil!
Let’s just think about the extreme of diagnosing coeliac disease: screening

- Common
- Missed diagnosis
- Cheap and good tests
- Treatable
- Prevent long-term damage

- WHO criteria for mass screening
The Prevalence of Adult Coeliac Disease in the UK is 1%!

- CD in Northern Ireland 1 in 122 (n=1823)
  Johnston SD et al *Lancet* 1997;350:1370

- CD in Sheffield 1 in 100 (n=1200)

- CD in Cambridge 1.2% (n=7550)

- CD in Bristol 1% (n=5470)
  Bingley P et al *BMJ* 2004;328:322-3
Screening criteria

- Common ✔
- Missed diagnosis
- Cheap and good tests
- Treatable
- Prevent long-term damage

- WHO criteria for mass screening
Modern concepts about coeliac disease!
Fassano A & Catassi C Gastroenterology 2001;120:636-51

- The commonest age for presentation is between the 4th to 6th Decade
- For every paediatric case diagnosed there are 9 adult cases
- For every adult case diagnosed there are 7 cases still not recognised
- People with undiagnosed adult coeliac disease generally have a normal BMI and may even be overweight
Screening criteria

- Common ✔
- Missed diagnosis ✔
- Cheap and good tests
- Treatable
- Prevent long-term damage

- WHO criteria for mass screening
## Serological tests

<table>
<thead>
<tr>
<th>Test</th>
<th>Sensitivity</th>
<th>Specificity</th>
</tr>
</thead>
<tbody>
<tr>
<td>IgA EMA</td>
<td>68-100</td>
<td>89-100</td>
</tr>
<tr>
<td>IgA TTG</td>
<td>38-100</td>
<td>25-100</td>
</tr>
<tr>
<td>DGPs</td>
<td>79-98</td>
<td>80-95</td>
</tr>
<tr>
<td>POCT</td>
<td>80-98</td>
<td>91-100</td>
</tr>
</tbody>
</table>

Depends on the population being tested

Screening criteria

- Common ✔
- Missed diagnosis ✔
- Cheap and good tests ✔ X
- Treatable
- Prevent long-term damage
- WHO criteria for mass screening
The cornerstone of management is the dietician with support from a gastroenterology consultant.
Screening criteria

- Common ✔
- Missed diagnosis ✔
- Cheap and good tests ✔✗
- Treatable ✔
- Prevent long-term damage

- WHO criteria for mass screening
Screening criteria

- Common ✔
- Missed diagnosis ✔
- Cheap and good tests ✔ ✗
- Treatable ✔
- Prevent long-term damage ✔❓
- WHO criteria for mass screening
So I could almost suggest that we could screen for coeliac disease let alone case finding!

But let’s see what happens in real screening programmes

Sanders DS et al BMJ 2008;336(7634):9

Subtle symptoms were present even in individuals who declared themselves as healthy volunteers
We are diagnosing and treating too many people with coeliac disease?

- **Screening**
  - The ‘individual’ or person considers themselves well
  - The physician/healthcare system has identified them as ‘ill’

- **Case finding**
  - Patient seeks medical help
  - Initiates consultation
  - Consents to investigation
### Diseases In Adults Associated With Coeliac Disease

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type 1 Diabetes</td>
<td>2-7.8%</td>
</tr>
<tr>
<td>Thyrotoxicosis</td>
<td>5-5.8%</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>3%</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>2.3%</td>
</tr>
<tr>
<td>Undefined Neurological disorder</td>
<td>17%</td>
</tr>
<tr>
<td>Infertility</td>
<td>3%</td>
</tr>
<tr>
<td>Cryptogenic Transaminasaemia</td>
<td>9%</td>
</tr>
<tr>
<td>IBS</td>
<td>3-5%</td>
</tr>
<tr>
<td>Idiopathic dilated cardiomyopathy</td>
<td>3-6%</td>
</tr>
</tbody>
</table>

- NICE. London, UK. 2009
General practice

Coeliac disease in primary care: case finding study
Harold Hin, Graham Bird, Peter Fisher, Nick Mahy, Derek Jewell

- N=1000
- EMA tested
- 30 new cases of coeliac disease

Costs per 100,000 population- ‘testing is cost effective from a QUALY perspective’

<table>
<thead>
<tr>
<th>Recommendations with significant incremental costs</th>
<th>Incremental costs (£ per year)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gastrointestinal specialists</td>
<td>6,812</td>
</tr>
<tr>
<td>Obtaining samples for serological testing</td>
<td>17,573</td>
</tr>
<tr>
<td>Intestinal biopsies</td>
<td>16,833</td>
</tr>
<tr>
<td>Serological testing</td>
<td>4,504</td>
</tr>
<tr>
<td><strong>Estimated incremental cost of implementation</strong></td>
<td><strong>45,722</strong></td>
</tr>
</tbody>
</table>
67-year-old Lady: *Typical History*

I would be most grateful for your advice concerning this lady who has been extensively investigated over the years for variable change in her bowel habit. Over the years she has had a barium enema which just shows scattered diverticulae, an ultrasound which has shown multiple stones in a thin walled gall bladder but I feel these have been asymptomatic. A colonoscopy, gastroscopy all revealed a hiatus hernia. However she is still complaining of marked bloating so we re-investigated her. Random biopsies, although the colonic ones were normal, the duodenal ones did show some subtotal villous atrophy and her anti gliadin antibodies are positive.

I have advised her therefore about her dietary needs but I know she would benefit from having your expert input in this situation.

With kind regards,
Primum non nocere
We are diagnosing and treating too many people with coeliac disease!!!
A quantitative and qualitative review of a multidisciplinary clinic for adults with Coeliac Disease

Catherine Foley
Specialist Gastroenterology Dietitian

Sister Shirley James
Specialist Gastroenterology Nurse
Coeliac Disease Management Guidelines

Clinical Resource Efficiency Support Team (CREST) 2006:

– Patients with coeliac disease (CD) should be seen by a dietitian within 2 weeks of diagnosis and reviewed at regular intervals.

British Society for Gastroenterology (BSG) 2010:

– All patients should see an experienced dietitian at diagnosis.
– Should be offered a review after 3-6 months.
Coeliac Disease

• Compliance with a gluten free (GF) diet reduces risk of complications including osteoporosis (Lewis & Scott, 2007).

• Adherence to strict GF diet is variable ranging from 36-96% (Hall et al, 2009)

• Regular specialist dietetic input is important to increase dietary compliance (Pietzak, 2005)

• Education of newly diagnosed patients should be carried out by an experienced team (Pietzak, 2005)

• A Multidisciplinary Team (MDT) approach for providing education is “the ideal” (Stuckey et al. 2009)
Formation of a Coeliac MDT clinic

- Coeliac service review (2008)
  - Patients waiting long periods to be seen in a non specialist dietetic clinic (3-6 months)
  - Patients seen by Gastroenterology Consultant at diagnosis and often reviewed before receiving any dietetic input

Specialist Coeliac MDT clinic led by Specialist Nurse and Specialist Gastroenterology Dietitian formed (2009)
Referral Pathway for Adult Coeliac Patients

Consultant grades GP referral letter indicating positive TTG*

Positive TTG identified by clinician in Outpatient Clinic

Endoscopist identifies positive duodenal histology at endoscopy

Newly diagnosed/Lost-to follow-up/non-concordant coeliac patient seen by Doctor in Outpatient Clinic

Coeliac patient transferred from Paediatric GI team

Referral to Specialist Nurse to carry out endoscopy

Inform Specialist Nurse

Appointment in MDT Coeliac Clinic Scheduled

*TTG: IgA tissue transglutaminase
Coeliac MDT clinic

- Explanation of diagnosis
- Check for nutritional deficiencies
  - Iron, calcium, vitamin D, folic acid, vitamin B12
- Gluten free diet explained
  - Prescriptions
  - Oats
  - Calcium
  - Cross-contamination
  - Coeliac UK
- Follow up plans, scans and repeat blood tests arranged
Aim

To evaluate patient satisfaction of a specialist MDT clinic for patients with coeliac disease
Methods

Developed questionnaire focused on patient experience of MDT clinic

Distributed to subjects who attended MDT clinic between January 2009 and June 2011

Comparisons between old versus new MDT service made
Results

120 invited to participate

74 (61%) responded

46 (39%) did not respond

29 (24%) provided general comments on their experience
## Results

<table>
<thead>
<tr>
<th>Satisfaction responses</th>
<th>Strongly Agree /Agree (%)</th>
<th>Neutral (%)</th>
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<tbody>
<tr>
<td>MDT clinic reduced hospital visits</td>
<td>90</td>
<td>9</td>
</tr>
<tr>
<td>Team approachable</td>
<td>99</td>
<td>1</td>
</tr>
<tr>
<td>Detailed information given on CD and its management</td>
<td>94</td>
<td>6</td>
</tr>
<tr>
<td>Left appointment feeling knowledgeable</td>
<td>94</td>
<td>5</td>
</tr>
<tr>
<td>Clinic offers means of accepting diagnosis and improving dietary compliance</td>
<td>87</td>
<td>13</td>
</tr>
<tr>
<td>Clinic offers timely and informative advice on CD</td>
<td>94</td>
<td>6</td>
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</table>
Results

- “I was impressed by the way the advice was presented and the interaction that existed between the differing specialities”
- “I came away feeling so positive about everything because the Specialist nurse and the Dietitian explained everything so clearly and with great patience”
- “The process was very smooth and efficient”
- “Very helpful to have both at one appointment”

Waiting Times:

- 8 % less than one week, 68 % 1-4 weeks, 24 % within 8 weeks
Discussion

- 87-99% satisfied with the MDT service
- Time saving for Consultant Gastroenterologist
- Model that could be implemented into other clinical and geographical areas.
Acknowledgements

- Dietetic and Gastroenterology colleagues in University Hospital Southampton
References

Powell-Tuck Prize Presentation
Treating occult coeliac disease with a gluten-free diet is associated with a significant improvement in quality of life

Lewis NR¹  Hubbard RH¹  Sanders DS²
Logan RFA¹  Holmes GKT³  West J¹

1. Division of Epidemiology and Public Health, University of Nottingham
2. Department of Gastroenterology, Royal Hallamshire Hospital, Sheffield
3. Department of Gastroenterology, Royal Derby Hospital, Derby
Living with Coeliac Disease

Controlled Study of the Burden of Illness


Psychological distress is common in prevalent coeliac disease

<table>
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<tr>
<th>Study design</th>
<th>Prospective studies</th>
<th>Retrospective studies</th>
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<tbody>
<tr>
<td>Case-control</td>
<td>Addolorato 2001</td>
<td>Ciacci 1998</td>
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<tr>
<td></td>
<td>Mustalahti 2002</td>
<td>Hallert 2002</td>
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<td></td>
<td>Collin 2008</td>
<td>Usai 2002</td>
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<td></td>
<td>Hopman 2009</td>
<td>Fera 2003</td>
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<td></td>
<td>Ukkola 2011</td>
<td>De Rosa 2004</td>
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<td>Siniscalchi 2005</td>
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<td>Viljamaa 2005</td>
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<td></td>
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<td>Roos 2006</td>
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<td></td>
<td></td>
<td>Addolorato 2008</td>
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<tr>
<td>Cohort</td>
<td>Casellas 2008</td>
<td>Ciacci 2002</td>
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<tr>
<td>Cross-sectional survey</td>
<td>Zarkadas 2006</td>
<td>Green 2001</td>
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<tr>
<td></td>
<td>Gray 2010</td>
<td>Ciacci 2003</td>
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<td></td>
<td>Barratt 2011</td>
<td>Hauser 2006</td>
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</table>
Improvement in quality of life in clinically-diagnosed coeliacs with GFD

Johnston et al Eur J Gas Hep 2004

n = 17
Improvement in quality of life with GFD in coeliacs presenting with GI symptoms

Mean SF36 scale scores

n = 97

Nachmann et al Dig Liv Dis 2008
No change in quality of life in screen-detected coeliacs with GFD

Johnston et al Eur J Gas Hep 2004

\[ p > 0.05 \]

n = 14
No change in quality of life with GFD in coeliacs with no GI symptoms and screen-detected disease

Nachmann et al Dig Liv Dis 2008

p > 0.05

n = 8 completing follow-up
Aims of prospective, longitudinal study

- What is the quality of life in contemporary incident coeliac disease?
- Does quality of life change on treating coeliac disease with a GFD?
Study population: Sheffield, Derby and Nottingham

Coeliac Register
Incident cases
of coeliac disease attending
Gastroenterology clinics
between 2007 – 2008
Study population: incident coeliacs

Classic presentation
- Weight loss and diarrhoea

Gastrointestinal (GI) symptoms
- GI symptoms *e.g.* diarrhoea in absence of weight loss, constipation, acid reflux

Occult disease
- No GI symptoms; or physiological derangements *e.g.* anaemia in absence of GI symptoms
Outcome ascertainment: Short-Form questionnaire (SF36)

<table>
<thead>
<tr>
<th>ITEMS</th>
<th>SCALES</th>
<th>Dimensions</th>
</tr>
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<tbody>
<tr>
<td>2. Change in reported health</td>
<td>Scale 1: Physical Functioning (PF)</td>
<td>Dimension A: PHYSICAL HEALTH</td>
</tr>
<tr>
<td>3. Vigorous activities</td>
<td>Scale 2: Role-Physical (RP)</td>
<td>Dimension B: MENTAL HEALTH</td>
</tr>
<tr>
<td>4. Moderate activities</td>
<td>Scale 3: Bodily Pain (BP)</td>
<td></td>
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<tr>
<td>5. Lift, carry groceries</td>
<td>Scale 4: General Health (GH)</td>
<td></td>
</tr>
<tr>
<td>6. Climb several flights</td>
<td>Scale 5: Vitality (VT)</td>
<td></td>
</tr>
<tr>
<td>7. Climb one flight</td>
<td>Scale 6: Social Functioning (SF)</td>
<td></td>
</tr>
<tr>
<td>8. Bend, kneel</td>
<td>Scale 7: Role-Emotional (RE)</td>
<td></td>
</tr>
<tr>
<td>9. Walk mile</td>
<td>Scale 8: Mental Health (MH)</td>
<td></td>
</tr>
<tr>
<td>10. Walk several blocks</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Walk one block</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Bathe, dress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Cut down time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Accomplished less</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Limited in kind</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Had difficulty</td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Pain-magnitude</td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. Pain-interfere</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. General health rating</td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. Excellent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>34. As healthy as anyone</td>
<td></td>
<td></td>
</tr>
<tr>
<td>33. Sick easier</td>
<td></td>
<td></td>
</tr>
<tr>
<td>35. Health worse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. Pep/life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. Energy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. Worn out</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31. Tired</td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. Social-extent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Social-time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Cut down time</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Accomplished less</td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Not careful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. Nervous</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. Down in dumps</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. Peaceful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. Blue/sad</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. Happy</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Statistical analysis

Quality of life according to presentation
Unpaired t-tests to compare SF36 scores between coeliacs presenting with GI symptoms, classic or occult disease

Change in quality of life with GFD
Paired t-tests to examine changes in SF36 scores from diagnosis in incident coeliacs to following 12 months treatment with GFD
## Presenting features of cohort

<table>
<thead>
<tr>
<th></th>
<th>Classic n=22</th>
<th>GI symptoms n=85</th>
<th>Occult n=44</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female (%)</td>
<td>13 (59)</td>
<td>54 (64)</td>
<td>27 (61)</td>
</tr>
<tr>
<td>Mean age (SD) y</td>
<td>56.9 (17.3)</td>
<td>47.8 (19.0)</td>
<td>52.4 (19.5)</td>
</tr>
<tr>
<td>Marsh grading (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3a</td>
<td>5 (23)</td>
<td>30 (35)</td>
<td>13 (30)</td>
</tr>
<tr>
<td>3b</td>
<td>8 (35)</td>
<td>23 (27)</td>
<td>16 (36)</td>
</tr>
<tr>
<td>3c</td>
<td>7 (32)</td>
<td>19 (22)</td>
<td>8 (18)</td>
</tr>
<tr>
<td>EMA positivity (%)</td>
<td>19 (87)</td>
<td>80 (92)</td>
<td>43 (98)</td>
</tr>
<tr>
<td>Median tTG [IQR] iu</td>
<td>114.7 [15–300]</td>
<td>112.1 [12–251]</td>
<td>133.9 [15–300]</td>
</tr>
<tr>
<td>Mean Hb (SD) g/L</td>
<td>12.6 (1.9)</td>
<td>12.8 (1.7)</td>
<td>11.4 (2.3)</td>
</tr>
<tr>
<td>Mean weight (SD) kg</td>
<td>62.0 (13.9)</td>
<td>73.1 (16.5)</td>
<td>70.0 (18.2)</td>
</tr>
</tbody>
</table>
# Quality of life at diagnosis of coeliac disease

<table>
<thead>
<tr>
<th></th>
<th>Mean SF36 (SD)</th>
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<tbody>
<tr>
<td></td>
<td>Physical health*</td>
<td>Mental health*</td>
<td>score*</td>
</tr>
<tr>
<td>All coeliacs</td>
<td>53.0 (21.5)</td>
<td>57.8 (19.7)</td>
<td>59.1 (19.5)</td>
</tr>
<tr>
<td>Classic disease</td>
<td>44.7 (23.3)</td>
<td>47.5 (18.6)</td>
<td>48.5 (18.8)</td>
</tr>
<tr>
<td>GI symptoms</td>
<td>51.8 (20.8)</td>
<td>57.6 (19.4)</td>
<td>57.4 (18.5)</td>
</tr>
<tr>
<td>Occult disease</td>
<td>59.1 (20.5)</td>
<td>63.2 (19.3)</td>
<td>67.6 (18.9)</td>
</tr>
</tbody>
</table>

*A score between 0 – 100 is given; a higher score indicates a better state of health*
Quality of life at diagnosis of coeliac disease

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<td>67.6 (18.9)</td>
</tr>
</tbody>
</table>

Mean difference SF36 score of occult versus classic disease = 19.1 [6.6, 26.2]
Quality of life at diagnosis of coeliac disease

- Classic disease
- GI symptoms
- Occult disease

SF36 score
Quality at life at diagnosis of classic and occult coeliac disease

SF36 score

Classic disease

Occult disease

PF physical functioning
SF social functioning
RP role physical
RE role emotional
BP bodily pain
VT vitality
GH general health
MH mental health
## Quality of life following 12 months GFD

<table>
<thead>
<tr>
<th></th>
<th>At diagnosis of coeliac disease (SD)</th>
<th>Following 12 months GFD (SD)</th>
<th>Mean difference in SF36 scores [95%CI]</th>
</tr>
</thead>
<tbody>
<tr>
<td>All coeliacs</td>
<td>59.1 (19.5)</td>
<td>77.7 (16.5)</td>
<td>18.5 [15.4, 21.6]</td>
</tr>
<tr>
<td>Classic disease</td>
<td>48.5 (18.8)</td>
<td>67.1 (25.1)</td>
<td>18.7 [8.4, 28.9]</td>
</tr>
<tr>
<td>GI symptoms</td>
<td>57.4 (18.5)</td>
<td>77.4 (14.1)</td>
<td>20.0 [15.9, 24.1]</td>
</tr>
<tr>
<td>Occult disease</td>
<td>67.6 (18.9)</td>
<td>83.2 (14.3)</td>
<td>15.5 [9.9, 21.2]</td>
</tr>
</tbody>
</table>
Quality of life following 12 months GFD

<table>
<thead>
<tr>
<th>Disease Type</th>
<th>At diagnosis of coeliac disease (SD)</th>
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</tr>
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</tr>
</tbody>
</table>

Mean percentage change in SF36 with GFD was similar whether the coeliacs had presented with GI symptoms, classic or occult disease.
Change in quality of life following GFD in coeliacs with GI symptoms

Change in SF36 score vs. SF36 score at diagnosis of coeliac disease with GI symptoms
Change in quality of life following GFD in occult coeliac disease

![Graph showing the change in SF36 score at diagnosis of occult coeliac disease.](image-url)
Interpretations

- Though incident coeliacs with occult disease were as likely to have villous atrophy and physiological derangement to those coeliacs presenting with GI symptoms or with classic disease, their reported mean quality of life was significantly better.
Interpretations

Following diagnosis and treatment of coeliac disease with a gluten-free diet we observed an improvement in mean quality of life:

- in classic, and occult disease; and in those presenting with GI symptoms
- that was similar regardless of presentation mode and the baseline quality of life

but this need not be directly causal