



Living with Coeliac Disease

Jane Davies
Coeliac Victoria and Tasmania Inc.

What is coeliac disease?

- Not an allergy or food 'fad', IBS or wheat intolerance
- An autoimmune response to gluten which is found in wheat, barley, rye and oats
- Associated with 2 genes – HLA DQ2 AND DQ8
- Twice as common as Type 1 Juvenile Diabetes
- On a par with the incidence of strokes

The impact

- 1 % of Australians
- Low diagnosis rates – 75% don't know
- Can be present from the age 4
- Average diagnosis - 40



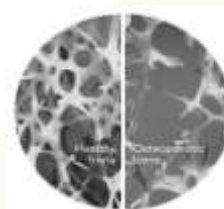
Imagine Grand Final Day



Untreated

.....coeliac disease can be serious

- Osteoporosis
- Infertility – men & women
- Neurological defects
- Anaemia
- Liver disease
- Joint pain
- Chronic fatigue



Common symptoms

- Diarrhoea or constipation
- Nausea and vomiting
- Abdominal pain, cramping/distention
- Unexplained weight loss
- Nutritional deficiencies
- Failure to thrive or faltering growth



SIMPLY "feeling out of sorts"

My symptoms



Very intermittent -

- Diarrhoea or constipation
- Abdominal pain, cramping

However definitely -

- Tiredness
- Nutritional deficiencies

Unfortunately -

- Did NOT suffer weight loss
- Symptoms not specific/regular enough for GP to think of CD.
- Looked for alternatives – visited naturopath

And then

After being tested on a VEGA machine:

Began following a wheat & dairy free diet –
WRONG ADVICE! No official illness established.

- Did not take seriously, only 95%

Never really understood why.

Did not really feel much better.

Not anaphylactic!

- On holidays – let diet go and was quite ill for 24 hrs.

In hindsight, sudden overload of wheat products
caused illness.

Coincidentally, time to visit GP (made a change)

New GP

Age 42 and time for thorough blood screen:

Cholesterol

Iron*

Folate*

B₁₂*

Pre-diabetes

Resulting in low levels *

Cholesterol, Pre-diabetes – no problems.

However, ate well – should not be low *

Why? Perhaps I had coeliac disease – next blood test confirmed elevated levels.

Referred to gastroenterologist

Small bowel biopsy - Positive

Further referrals to:

Dietitian – nutritional support

Coeliac Victoria & Tasmania – membership and ongoing support

Lucky to be diagnosed

What have I learned?

Correct diagnostic procedure



No matter where the patient visits first – if they have symptoms or just feeling out of sorts:

- DO NOT start patient on a GF diet until tested for coeliac disease. (6 weeks, equiv. to 2-4 slices of bread)
- Suggest CD test (Coeliac serology via GP)
- Positive – confirm with small bowel biopsy
- Negative – further follow up

REMEMBER:

Gene test rules coeliac disease out – not a diagnosis! Only 1 in 30 with the gene have CD

COELIAC DISEASE

Affects up to 1% of the community. Mostly (but not exclusively), Caucasians, Middle Eastern and West-Asian (Indian/Pakistani)

Age of presentation: 6 months to 90+ years

Diagnose

Test children and adults with:

- Iron deficiency and anaemia
- Osteoporosis
- Recurrent abdominal pain, diarrhoea and weight loss
- Unexplained elevated transaminases
- Peripheral arthritis
- Mouth ulcers
- Insulin-treated diabetes
- Chronic fatigue
- Headaches
- Infertility
- In children: developmental delay, short stature
- Coeliac disease is a first-degree relative

Test

Tryptoglobulin IgA + total IgA
 Deaminated gliadin peptide IgA & IgG
 Blood tests do not confirm coeliac disease
 Blood tests detect >90% untreated coeliac disease if gluten regularly eaten
 HLA-DQ gene test can exclude coeliac disease even when gluten not eaten
 Gastroscopy with biopsy of small intestine is mandatory to diagnose coeliac disease



For information on our support, contact Coeliac Australia
www.coeliac.org.au

1300 458 836

INCREASED RISK OF COELIAC DISEASE?



How the gut damage looks?

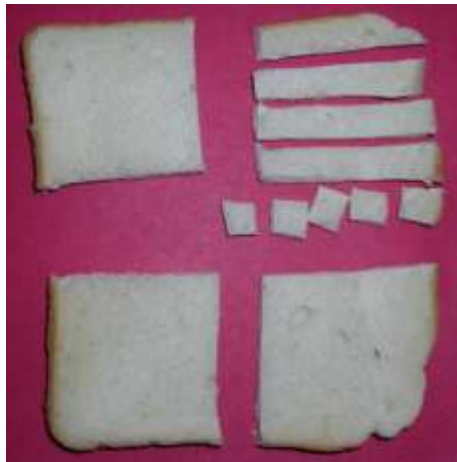
Normal Villi



Damaged Villi



1 x 100th of a slice of bread



Important to follow diet

RELATED CONDITIONS

- Thyroid disease
- Dermatitis Herpetiformis
- Type 1 Diabetes
- Dental enamel defects
- Depression
- Lymphoma
- Sjogren's syndrome

..... and many more

Family Screening

- First degree relative 10%
- Identical Twin – 70%
- When other auto immune conditions are present
- Worth getting gene test at same time to rule CD out.
- Little children without symptoms – mouth swab
- Otherwise, can request both tests at same time.



Is there a cure?

NOT YET,
but currently research into:

- Vaccine
- Peptide development



In the meantime, patient must maintain a strict gluten free diet for life.



Gluten free
food only

ONLY TREATMENT

A Gluten Free Lifestyle

Shopping

- Attend Great Start Workshop
- Endorsed products
- Ingredient Booklet – only available through Coeliac Australia State offices (NOT FOOD LISTS)
- List of food stockists
- Speciality stores, supermarkets



Label Reading Tips

- Glucose & Dextrose OK even if derived from wheat
- Dextrins NOT OK (unless unidentified)
- Caramel Colour from wheat OK
- All labels in Australia must declare allergens
- Imported foods must comply



FSANZ (Food Standards Australian and New Zealand)

Dining Out

- Always ring ahead
- Always ask questions
- Restaurant List on CVT website
- Professional membership to food industry
- Cross contamination
- Menu Matrix



Travel

Not so hard these days as CVT has developed some great resources

- Gluten Free Travel Guide
- iPhone and Android App
- Business size language translations
- General Travel Tips
- Lunch on the go
- About Gluten Standards in other countries



Students

Resources are available for all levels of education

- School canteens
- Gluten Free management for teachers
- Kid's lunch box ideas
- School camp facilities
- Annual events for various age groups



Overall health

- Coeliac disease is a chronic condition
- Follow up biopsy
- Blood tests
- Remember other linked conditions



Why join

- Starter Kit
- Full colour magazine
- Lifestyle resources
- Workshops
- Recipes
- Age appropriate events
- Advocacy
- Regional contacts
- Support Centre
- GLUTEN FREE EXPO



In summary

- Encourage patients to follow the correct path to diagnosis
- If already on a gluten free diet, recommend a challenge.
- A positive diagnosis is a good thing – better to know than not.
- Once diagnosed, recommend membership of Coeliac Victoria and Tasmania for ongoing support.

Thank you from



Contact:

Jane Davies, Executive Officer

VicTasEO@coeliac.org.au

Phone: 1300 458 836

www.coeliac.org.au/vic-tas

9-11 Barlyn Road, Mt Waverley 3149